Predictors of Emergency Room Visits or Acute Hospital Admissions Prior to Death among Hospice Palliative Care Clients in the Community

by

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Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Background: The demand for hospice palliative care (HPC) services is expected to grow due to the increasing number of seniors living into advanced old age, the changing nature of death, and the changing family structure. HPC is a philosophy of care that aims to relieve suffering and improve the quality of life for clients with life-threatening illnesses or end of life issues. The goals of HPC are not only to ameliorate clients' symptoms but also to reduce unneeded or unwanted medical interventions such as emergency room visits or hospitalizations (ERVH). Hospitals are considered a setting ill-prepared for end of life issues. Therefore, use of such acute care services has to be considered an indicator of poor quality end of life care. It is important to understand the factors that contribute to ERVH in order to determine how to minimize the number of avoidable hospital visits.

Objectives: The objectives of this study were to report the proportion of palliative home care clients with ERVH, describe the characteristics of clients with ERVH, and identify the predisposing, enabling, and need-for-care variables associated with ERVH.

Methods: Analysis of secondary data was performed on a palliative home care dataset from the Hamilton Community Care Access Centre (CCAC). All palliative home care clients receiving services from the Hamilton branch were assessed using the interRAI Palliative Care (interRAI PC), which is a comprehensive, standardized instrument. One assessment for each client assessed between April 2008 and July 2010 was used, for a final sample size of 764.

Results: Half of the palliative home care clients had one or more ERVH. Visits to the emergency department by time of the day and day of the week were relatively stable. Logistic regression and Cox regression analyses showed that wish to die at home and advance care directives are

protective against ERVH. Unstable health, identified by a Changes in Health End stage disease and Signs and Symptoms scale (CHESS) score of 3 or higher, was associated with reduced odds of ERVH, while infections such as prior pneumonia and prior urinary tract infections increased odds of ERVH.

Conclusions: Predisposing characteristics (i.e., wish to die at home and advance care directives) are nearly as important as need variables (i.e., CHESS and prior urinary tract infection) in determining ERVH among palliative home care clients, which challenges the assumption that need variables are the most important determinants of ERVH. There was a lack of significant association between many assessed needs and ERVH, perhaps due to the fluctuating health status among such clients and the stability of measurements. Ongoing assessment of palliative home care clients is essential in reducing ERVH, as reassessments at specified intervals will allow care and service plans to be adjusted with clients' changing health needs and end of life preferences.

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Dedication

This thesis is dedicated to my fiancé Ryan for his endless love, patience, and constant encouragement.

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List of Abbreviations

ADLH	Activities of Daily Living Hierarchy scale
CHESS	Changes in Health End stage disease and Signs and Symptoms scale
CHRIS	Client Health Related Information System
CI	Confidence Interval
CPS	Cognitive Performance Scale
DAD	Discharge Abstract Database
DNR	Do-Not-Resuscitate
DRS	Depression Rating Scale
EAP	Exceptional Access Program
ED	Emergency Department
ERVH	Emergency Room Visits or Hospitalizations
HPC	Hospice Palliative Care
HR	Hazard Rate
interRAI	Group of International Researchers (www.interrai.org)
interRAI PC	Resident Assessment Instrument for Palliative Care
LTC	Long Term Care
LHIN	Local Health Integrated Network
LHIN IDS	Local Health Integrated Network Integrated Data Stores
PE	Parameter Estimate

MOHLTC	Ministry of Health and Long Term Care
MRP	Most Responsible Physician
NACRS	National Ambulatory Care Reporting System
OACCAC	Ontario Association of Community Care Access Centres
ODB	Ontario Drug Benefit
OR	Odds Ratio
SD	Standard Deviation
SE	Standard Error
SES	Socioeconomic Status

Chapter 1

Introduction

The number of Canadians aged over 65 years is growing rapidly as one in three baby-boomers, born between 1946 and 1965, began to reach the age of 65 in 2011 [1]. The 2011 census data revealed that the 65 and older population made up a record of 14.8% of the total population of Canada, and it is expected that the proportion of seniors could nearly double within the next 25 years [1]. A key factor in our ageing population is the increase in life expectancy. Canadians are living longer with individuals over 65 expecting to live up to an additional 20 years [2]. Regardless of this longer life expectancy every individual in Ontario will die. Only 10% will die suddenly, but 90% will require support with end of life care [3].

The nature of deaths is changing because the majority of deaths are attributed to chronic diseases [4]. There are four trajectories of death typical of the changing nature of deaths: the first is sudden death from an unexpected cause; the second is a decline in health status due to a disease with a terminal phase such as cancer; the third is one of acute episodes requiring hospital admissions, and eventually death occurs during one of the acute episodes; and the fourth, also the most common, is a prolonged dying process due to advanced chronic illness such as heart disease, stroke, chronic obstructive pulmonary disease, renal failure, and Alzheimer's disease [5]. The increasing number of seniors and the increased life expectancy will result in more and more individuals living with chronic conditions and for a longer period of time [6]. These individuals require highly individualized care from an interdisciplinary team of health care professionals who provide increased communication with caregivers and offer medical and social services, as well as pain and symptom management [7].

Because seniors are living for a longer period of time and with more chronic conditions, they rely on family members to receive informal care; however, the family structure is continuously changing [8]. For example, the average family size has decreased over the years, leaving seniors today with fewer children on whom they can depend for care [9]. Furthermore, since the dual wage earning trend is continuing to grow, there are many more women in the labour force. Family caregivers have traditionally been and will continue to be women [8], so the availability of informal caregivers will decrease. In the future, there may be even more demand for care than caregivers can provide [8, 9].

The demand for hospice palliative care (HPC) services is estimated to grow due to the increasing number of seniors living into advanced old age, the changing nature of death, and the changing family structure. The World Health Organization defines HPC as "An approach that improves the quality of life for those facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [10]. The philosophy of care is client and family centred, respecting their social, spiritual and cultural practices. It aims to treat all active issues and prevent new issues from occurring; helps clients and their families prepare for and manage self-determined life closure and the dying process; and offers families support for coping with loss and grief during illness and bereavement [5].

HPC can be provided in a variety of settings including a client's home, an inpatient hospice facility, a specialized HPC unit in a hospital, and a continuing care facility [11]. A multidisciplinary team of healthcare providers including physicians, nurses, physiotherapists, occupational therapists, social workers, chaplains, home health aides, and volunteers [12], assist clients with life-threatening illnesses or end of life issues. This assistance is given for any

prognosis, at any age, and at any time clients have unmet expectations or needs [13]. Clients and their families must understand that the goal of care is quality of life, rather than cure of illness [14]. The Hospice Palliative Care Association has estimated that no more than 37% of Canadians currently have some level of access to or receive HPC services appropriate for their needs [1, 15]. As clients approach death, more service hours are put in place to meet their increasing needs at home rather than in a hospital [14].

The goals of HPC are not only to ameliorate clients' symptoms but also to reduce unneeded or unwanted medical interventions such as emergency room visits or hospitalizations *(ERVH) because hospitals are considered a setting ill-prepared for end of life issues [16, 17, 18]. Yet almost 60% of deaths occur in hospital settings [15, 19]. In Ontario, a retrospective study conducted in 2001 reported that 27% of deceased cancer clients had at least one emergency department visit in their last two weeks of life and that 67% of these visits led to an admission [19]. Another study conducted between 2002 and 2005 discovered that 84% of cancer patients visited the emergency department in the last six months of life and 40% of those were in the last two weeks [2]. The statistics for three other provinces are comparable to those of Ontario. In Manitoba and Saskatchewan, between 2003 and 2004, many HPC clients were hospitalized at least once in the last six months of their lives [20]. In Nova Scotia, Burge et al. (2003) conducted a retrospective study of adult cancer clients who died between 1992 and 1997 and reported that, although most HPC clients preferred to spend their last days out of hospital, many made visits to the emergency department. Out of a total of 8,702 identified clients about 56% made at least one emergency department visit in the last six months of life [21].

Costs are significantly higher to receive end-of-life care in an acute care hospital than costs associated with similar care at home [1]. For example, in Ontario, the cost of providing

*ERVH includes emergency room visits only, emergency room visits leading to acute hospital admissions, or acute hospital admissions only

palliative care in an acute setting is approximately $19, 900 per patient annually [22]. On the other hand, the cost of providing palliative care in the home including costs related to other non-palliative services is approximately $4,700 per client annually, resulting in a cost differential of $15, 200 per client [22].

Emergency room visits leading to admissions disrupt continuity of care, may be contrary to the client's goals of care, cause changes in the focus of care, and compromise the client's quality of life and quality of care [23, 24]. Since ERVH can be very disruptive, distressing, and exhausting [25], the use of such acute care services has become an indicator of poor quality end of life care [26, 27, 28].

The culture of care provided in HPC and ERVH vary greatly. When individuals enter HPC, everyone involved acknowledges and accepts that death is imminent and agrees to forgo curative therapies [21]. The primary function of the ERVH is to diagnose and treat traumatic or acute events [21] and there is little time for discussion of advanced care planning and death [29]. ERVH may not be appropriate for HPC individuals since hospital clinicians have limited relationships with clients and families and do not have knowledge of the clients' immediate illness situation, wishes, or values to guide decisions around end of life care [29]. Further, the mission to prolong life is very pronounced in hospitals and so the focus is on aggressive and lifesaving interventions. The culture of saving lives in hospitals may be in conflict with alleviating suffering and are often not in accord with needs and preferences of clients and their families in a HPC program [16, 30, 31].

Hospitals are not designed to provide a good quality death. They have become more congested due to increased demand for care and increased complexity of care. The overcrowding

of emergency departments has implications for client outcomes, as the efficiency and effectiveness of care are compromised [32]. During times of overcrowding, patients may experience prolonged pain or suffering due to wait times and physicians may have reduced productivity and inadequate time for proper patient assessments, which may lead to medical error [32].

HPC utilization should affect clients', families', and caregivers' predispositions to forego ERVH. The services should be able to prepare clients and families to meet death with dignity and without disruption of ERVH. To provide HPC services that produce outcomes valued by clients and families, it is important to understand the factors that contribute to ERVH, as it is crucial for determining how to best attempt to minimize the number of visits.

Chapter 2

Palliative Care Service Provision in Ontario

2.1 Palliative Home Care

In Ontario, Community Care Access Centres (CCACs) are 100% funded by the Ontario Ministry of Health and Long-Term Care (MOHLTC) to provide simplified access to home and community care; to deliver and make the arrangements for the delivery of home care services to people in their homes, schools and communities; to provide information and referral to the public on community-related services; and to authorize admissions to long-term care (LTC) homes [33]. The CCAC boundaries align with the geographic boundaries of Ontario's 14 Local Health Integration Networks (LHIN) (Appendix A). There are no age restrictions or charges for services provided, and the duration of services depends on clients' needs. CCAC services enable clients to remain at home for as long as possible and delay or prevent admission to hospitals or LTC homes [33].

Individuals requiring services can refer themselves for CCAC services, or they can be referred through a family member, caregiver, friend, physician, or other health care professionals [33]. In order to be eligible for any CCAC services, clients must be an insured person under the MOHLTC *Health Insurance Act*, services must be necessary to enable clients to remain in their homes, and services must be expected to result in progress towards palliation [34]. In addition, clients' homes must have the physical features necessary to enable services to be provided [35].

Case managers working at each centre are responsible for coordinating service delivery provided by the CCAC, the contracted service providers, and the caregivers [35]. The case managers assess client needs, determine eligibility for services, and identify the nature, intensity,

and duration of services required. The assessment ensures that the right services are provided to clients at the right time, and reassessments can be done on an as needed basis.

2.2 Criteria for Assigning Clients to a Palliative Caseload

Clients are admitted to a palliative care caseload and nursing is ordered immediately based on the following criteria: clients have a life limiting or life threatening health condition, regardless of diagnosis; clients may have a prognosis of six months or less to live; or clients have pain and symptom issues related to end of life conditions [36].

2.3 Payment for Palliative Care Services

Home and community care is delivered by regulated health care professionals (e.g., nurses, occupational therapy, social work services, nutritionist/dietician, and speech language pathology), volunteers, friends, and family caregivers [35, 37]. Home care services are not publicly insured through the Canada Health Act in the same way as hospital and physician services. In Canada, most home and community care services are delivered by provincial, territorial, and some municipal governments. The federal government provides funding support through transfer payments for health and social services [33].

Legislation governs the amount of and circumstances for services provided by CCACs. For palliative care clients, CCACs have the ability to provide higher level of service to support them to remain at home for end of life care [15, 33].

2.4 Palliative Care Clients Admitted to a Palliative Care Unit

Care provided in a hospital may be slightly different than care provided in a client's home because in a hospital setting the health care team is able to provide care 24 hours a day, 7 days a week [38]. Some hospitals may have specialized units for palliative care while others may

set aside a certain number of beds, however the number of beds vary considerably. Palliative care provided in hospitals is usually paid for by provincial health plans. Plans cover most care including medication, medical supplies, and equipment while clients are in the hospital [37]. Clients may be admitted to a specialized palliative care unit if the focus of care is comfort rather than cure of illness, if a do not resuscitate status has been agreed upon, and if the individual has an estimated life expectancy of 3 months or less [39]. If the individual's health condition stabilizes or improves, they are transferred to a more appropriate care setting. The average length of stay in hospitals for palliative care clients is currently 13.5 days [40].

2.5 Ontario Drug Benefit Plan

The Ministry of Health and Long-Term Care covers most of the costs of prescription drug products listed under the Ontario Drug Benefit (ODB) Formulary, as well as for other exceptional cases [37]. Individuals aged 65 years and over are eligible for the ODB plan. Individuals who are aged 64 years and under, who need at least one professional service in the home are eligible for a drug card which remains in place for the entire duration of the treatment period and may be renewed if the client is still receiving professional services [37]. Case managers fill out the Drug Benefit Eligibility card, which is then forward by the CCAC to the MOHLTC [37]. If drug products are not listed on the Formulary, they are considered for coverage through the Ministry's Exceptional Access Program (EAP) on a case-by-case basis when requested by a client's physician. Specific products used to treat ODB-eligible clients undergoing palliative care are reimbursed through the Facilitated Access process under the EAP; therefore, physicians do not need to obtain approval under the EAP for palliative clients [41].

2.6 Hospice Palliative Care in United States

In Canada, HPC represents a certain philosophy care; thus the terms “hospice” and “palliative care” are used interchangeably. Hospice care usually refers to services received in a hospice facility, while palliative care refers to services provided in the community. In contrast, in the United States, the terms are not always used interchangeably. Palliative care services are generally offered to clients who have received a diagnosis of a serious illness, regardless of prognosis, and life prolonging and curative therapies continue to be available [42]. Medicaid provides significant coverage for palliative care, found increasingly in hospitals [43]. Hospice care refers to services provided in a hospice facility, as well as in the home. Americans are eligible for hospice care services if they have a terminal illness, prognosis of 6 months or less to live, and agree to forgo curative treatments and focus on maximizing comfort and quality of life [42]. Clients who meet the eligibility criteria for hospice care are also eligible for the Medicare Hospice Benefit which pays for all required services, medical equipment, supplies, and medications related to the terminal condition [44].

Chapter 3
Literature Review

The literature review will provide evidence for use of HPC programs to reduce ERVH, explore the prevalence of ERVH, and examine individual characteristics predicting use of ERVH. The review will also provide a critical appraisal of literature on HPC and ERVH.

Studies reviewed included: HPC provided in home, hospice, or continuing care facility, participants with terminal illnesses, prognosis of 1 year or less to live, hospital or emergency department visited, varied observation periods (i.e., 1 year, 6 months, 3 months, 1 month), research designs, and methodological approaches. Studies that investigated paediatric populations (age 18 years and under), hospital based palliative care, and palliative care consultation in hospital were excluded.

3.1 Hospice Palliative Care and Reduced Emergency Room Visits and Acute Hospital Admissions

One of the ways to evaluate the effectiveness of HPC is to examine time spent in hospitals because reduction in ED visits is one of the main goals of palliative services. Studies conducted in the United States have compared rates of ERVH among clients enrolled in a hospice program against those of clients receiving conventional care at the end of life. Bergman and colleagues (2009) reported that clients enrolled in hospice care experienced fewer ERVH. Among clients not enrolled in hospice care, 63% made an ED visit, while only 21% of enrolled clients made an ED visit [45]. Hospice care delivered in nursing homes was also found to be associated with lower rates of hospitalization in the last 30 days of life; 1% of hospice clients compared to 42% of non-hospice clients experienced at least one hospitalization. Hospice care was found to improve symptom management, quality of life, and quality of death [45]. Miller

and colleagues (2001) suggested that reductions in hospitalizations are a function of closer medical management by physicians or physician assistants and of the capacity of service providers to meet the needs of dying clients within the hospice facility [46].

Italian studies have also found that enrolment in an HPC program resulted in reduced ERVHs; however, the differences were more evident in the last couple of months of life and disappeared in the last 6 to 12 months of life. Constantini and colleagues (2003) reported that 20% of palliative clients versus 24% of non-palliative clients experienced an ED visit in the last 60 days before death. In the last 30 days of life, these numbers changed to 19% and 40%, respectively [47]. Further, Miccinesi and colleagues (2003) determined that among clients not receiving palliative care, 67% experienced at least one hospital admission in their last 3 months of life compared to only 53% of clients who received palliative care in the same period. Surprisingly, during the last year of life, aside from the last 3 months, 49% of palliative clients experienced an admission compared to 38% of non-palliative clients [17]. This finding suggests that length of time spent in palliative care does not seem to have any significant impact on number of ED visits by palliative clients.

3.2 Contributing Factors to Emergency Room Visits and Acute Hospital Admissions

One of the goals of palliative care is to limit ERVH because it may compromise the quality of care and quality of life of clients. Given this objective, studies have tried to identify factors to explain why HPC clients experience ERVHs. A Canadian study, conducted by Lawson and colleagues (2008) reported that 27% of palliative clients in a home care program, outpatient clinic, and inpatient unit made at least one visit to the ED in the last 6 months, and 54% of these visits resulted in hospital admissions. The primary reasons for the ED visits included pain and shortness of breath, and the visits were not associated with time of day or day of the week [48].

Additionally, the study suggests that clients cared for by a parent or relative were more likely to visit the ED compared to those whose caregivers were a spouse or partner [48]. Clients who were younger or who lived in a rural location were also more likely to make ED visits [48]. Brink and colleagues (2011) conducted a study in Ontario, Canada and reported that 35% of palliative home care clients visited the ED and that the main determinants of ED use included weight loss and previous hospitalization [49]. These two determinants increased the likelihood of ED use, while lower cognition levels reduced the likelihood [49].

Studies conducted in the United States have reported that rates of hospitalization among clients enrolled in a hospice program ranged between 6% to 17% [18, 24]. Primary reasons for admissions included bone fractures, delirium, and pain [18, 23, 24]. In addition, some studies suggest that African American clients have higher rates of hospitalizations [18], while rates were lower for clients who were female, Caucasian, aged 85 years and older, with do not resuscitate orders, and increased nursing services [18, 23, 24].

3.3 Methodological Issues

Although there has been literature pertaining to HPC and ERVH, some have been characterized by important methodological issues. The 9 studies discussed in the above section will be evaluated in this regard. Sample characteristics and key findings from each study can be seen in Appendix B and C.

3.3.1 Study Design

Of the 9 studies reviewed, 8 used a retrospective cohort design and one used a prospective cohort design. A cohort study design is advantageous since it does not require strict random assignment of subjects. Although randomized control trials are the strongest design for making causal inferences about the effect of HPC enrolment on reduced ERVH, HPC is believed

to be superior to conventional care and consequently it is deemed unethical to encourage participants to be in a randomized control trial [50]. Due to lack of randomization, the exposed (HPC enrolment) and unexposed (conventional care) groups may differ in ways other than the variable under study. For example, individuals who continue to receive conventional care rather than HPC at the end of life may be unaware of their prognosis, may have not accepted the fact that death is inevitable, may still want to continue curative therapies and therefore may be more inclined to go to the hospital to receive more aggressive treatments. Cohort studies are subject to the influence of factors over which the investigators often do not have control and so studies are more open to threats to internal validity than studies with experimental research designs. However, this design clearly demonstrates an appropriate temporal sequence between exposure and outcome (ERVH).

Constantini et al. (2011) identified their study as quasi-experimental in design, however, based on the methods used it resembled a retrospective cohort study [47]. Quasi-experimental designs examine the exposure and the outcome during the course of the study, however, exposure and outcome data were previously collected since files of individuals who died from cancer in 1991 were reviewed to identify individuals referred to HPC, and hospital records were then examined to assess the outcome.

3.3.2 Sample Size & External Validity

Most studies had large sample sizes ranging from 500 [47] individuals to 16,000 [18], while 3 studies had sample sizes of less than 100 [23, 24, 45, 49]. Small samples sizes may result in underrepresentation of the target populations, perhaps lead to type II error due to low power, and consequently the authors may incorrectly find no differences in risk of ERVH between those enrolled in a HPC program and others receiving conventional care.

Generalizability of findings varied among the studies, with the majority only examining specific types of terminal illnesses, i.e., end stage cardiac disease [21], prostate cancer [45], lung or colorectal cancer [18], advanced cancer [17, 47, 49]. A few others examined hospice clients in general, without specifying their diagnosis [24, 46, 48]. The studies which included certain types of diagnosis only allow for generalization of findings to populations with the same diagnosis, while the other studies which included individuals with any diagnosis had increased external validity.

3.3.3 Bias

Although all of the studies used administrative and medical records, they were still subject to non-response bias. Some individuals may have been referred to HPC but refused the services. In addition, individuals who were not receiving HPC and experiencing certain end of life symptoms could have still refused to receive medical care from hospitals. Therefore, these individuals may be systematically different from those who accepted services. The studies are further limited by attrition bias as some clients may have moved away during the period of care or may have decided to stop receiving care. Therefore, these individuals may also be systematically different from those who continued to receive care. Both of these biases may have had an influence on the association between HPC enrolment and reduced ERVH. For example, individuals who accepted HPC services and continued to receive care, may be individuals who were aware of their prognosis, were accepting of their inevitable death, and therefore were more likely prefer comfort care provided at home rather than aggressive treatments provided in hospitals.

Referral bias was also present because clients who were referred to HPC may have been different than clients who were not [47]. Referral patterns may be different based on diagnosis,

for example end stage dementia is not always viewed as a terminal illness from which one dies and so individuals suffering from the illness are less likely to get referred to HPC [51]. Selection bias is another factor that cannot be adjusted. Although the unexposed groups would have perhaps preferred HPC, they may have been unable to enrol due to limited access to the service, may have been unaware of the services or may have not had Medicare. The presence of selection bias may have affected external validity of the studies.

3.3.4 Measurement of Exposure and Outcome

All studies examined at least a few of the following databases to determine HPC enrolment and ERVH: administrative health databases, HPC enrolment records, Medicare files, census data, cancer registries, emergency department information systems, cancer registries, and mortality registries. Some of the databases used have strengths because they may have complete, accurate, and reliable data. However, there may be major limitations to the use of some existing data files as they may have inaccurate or incomplete data resulting in error.

Although reasons for ERVH were documented, only a few studies used procedure codes to identify aggressiveness of care such as having an invasive procedure, receiving chemotherapy or radiotherapy, or other therapies [18, 23, 24]. These studies had strength in measuring the intensiveness of care because it allowed for identification of clients receiving bladder catheter placements which cannot be performed in a HPC setting and clients receiving cardiopulmonary resuscitation [18].

Miller et al. (2001), Schonwetter et al. (2008), and Brink et al. (2011) were alone in determining if clients had advance care directives to convey clients' wishes about end of life care [23, 46, 49]. Miller et al. (2001) adjusted for do-not-resuscitate (DNR) orders, Schonwetter et al.

(2008) reported that individuals with a DNR had reduced risk of going to the hospital, and Brink et al. (2011) did not find DNRs to be significant. Olsen et al. (2011) were alone in identifying documented client goals of care and reported that care received by clients did not match previously documented goals in 25% of admissions [24]. These measures are important because they provide explanations for different hospitalization rates following HPC entry. When individuals enroll in a HPC program, the understanding is that the goal of care is quality of life rather than quantity. However, they may change their minds about foregoing aggressive therapy and want to receive more aggressive treatments in hospitals [18]. Further, Lawson et al. (2008) was alone in examining ERVH across time and reported that very little variability was observed either by time of the day or day of the week, which indicates that there were no specific time periods that should have been targeted for lack of services available [48].

It is essential that a clear definition of HPC be provided as eligibility criteria and service provisions may differ depending on the country or even province. Only Bergman et al. (2009) and Miller et al. (2001) provided clear definitions, thereby making it very difficult to compare most study findings [45, 46]. Since there is a general lack of definition provided for HPC, the extent to which the exposed and unexposed groups differed is unclear.

Not only is the definition of HPC important but also the length of time enrolled in the program. All the reviewed studies, except for Miller et al. (2001), Schonwetter et al. (2011), and Brink et al. (2011), reported median time spent in HPC before death (ranged from 25 days [18] to 68 days [48]). However, only Bergman et al. (2009) took into consideration the effects of the duration of enrolment. Differences between individuals receiving HPC and those not receiving such care were found to be greater when comparing clients who were enrolled for a longer period

of time [45]. The differences in duration of enrolment in a HPC program before death could have resulted in the varying strengths of association between HPC and reduced ERVH.

3.3.5 Potential Confounders

The main confounders adjusted for were age, gender, and marital status, all of which are very important factors. Some studies have indicated that younger individuals are more likely to be referred to and use HPC services, while older adults have reduced access [52, 53, 54]. When gender is paired with either age or marital status, it also tends to influence HPC service utilization [55, 56, 57]. Not only are they confounding variables for HPC but also for hospitalization [47]. The following factors have been associated with increased likelihood of ERVH: older age, female sex, and never married [23, 24, 46, 47, 48].

Half of the reviewed studies had information on race, which is a great strength since ethnic minorities are reported as having increased ERVH. Ethnic minorities are more likely to prefer life-sustaining therapies, to reverse do-not-resuscitate status, and select aggressive interventions [17, 23, 45, 46]. Conversely, Caucasians have increased use of hospice care and reduced usage of high intensity care at the end of life [60]. Some U.S. studies showed that individuals from minority ethnic groups also tend to have reduced access to and use of HPC [56, 58, 59, 60]. In the U.S, African-Americans have been reported to be more likely than Caucasians to use emergency departments in general, which may result from differences in health-seeking behaviours [61]. It is important to note that the above findings may not apply to ethnic minorities in Canada.

A few of the studies also had measures on geographic residency. This is another great strength because individuals in rural areas are reported as having increased ERVH, primarily due

to limited access to HPC [17, 18, 24, 45, 48]. Many rural communities may lack HPC coordinators, social workers, volunteer services, and 24-hour HPC coverage [61, 62]. Therefore, when individuals experience end of life issues, they are more likely to visit ERVH since they lack access to HPC services [48].

Unfortunately, none of the studies examined hospice characteristics that could have potentially influenced hospitalization rates, e.g., quantity and quality of resources, staffing level, and quality of care. In addition, not all of the sample characteristics that predispose them to elect HPC were adjusted for (e.g., education and religion). Only two studies adjusted for education [23, 47]. Individuals with lower education may have reduced health literacy, thereby affecting their ability to make appropriate decisions regarding use of HPC services [62]. Moreover, if individuals feel as though their religious needs will not be adequately addressed during the dying process, they may be less likely to use the HPC services [63].

3.4 Bradford Hill Criteria of Causation

In 1965 Sir Austin Bradford Hill, a British medical statistician, outlined conditions needed to establish a causal relationship between specific factors and an outcome [64]. Now known as the Bradford Hill criteria, this tool has been widely used in science and law to determine causation when an association is observed [64]. The weight of evidence that each criterion contributes is a matter of subjective interpretation. Only 5 criteria that were appropriate for establishing an argument of causation in palliative research were applied. Herein, the criteria will be applied in order to establish a valid connection between HPC enrolment and reduced ERVH, and determine causal links between potential predictors and ERVH.

3.4.1 Strength of the Association

Constantini et al. (2003) reported that after HPC enrolment the percentage of days spent in hospital increased for both exposed and unexposed groups; however, the percentage was significantly higher in the unexposed group (95% CI 12-17) [47]. Miller et al. (2001) also reported that individuals enrolled in HPC programs were less likely to experience an ERVH (odds ratio 0.43, 95% CI 0.39 - 0.46) [46]. In addition, Miccinesi et al. (2003) determined that the exposed group had a 25% reduction in relative risk (95% CI 14-34) of ERVH and a 49% reduction in relative risk of spending days in emergency departments (95% CI 47-52), compared to clients receiving conventional care [17]. Only Bergman et al. (2009) found no difference in the number of ERVH between those enrolled in a HPC program and those receiving conventional care services ($p=0.15$) [45].

Brink et al. (2011) reported that clients with weight loss were four times (odds ratio 4.3, 95% CI 1.4 - 13.5) more likely to visit an ED and those who were previously hospitalized were more than three times as likely (odds ratio 3.5, 95% CI 1.2 - 10.4) [49].

3.4.2 Consistency

All of the reviewed studies, except for two [23, 24], cited other papers that reported similar findings although they involved different populations. Specifically, Constantini et al. (2003) cited a study reporting that senior populations enrolled in a home care program also had reduced risk of hospital admission [47]. Miller et al. (2001) cited studies from two decades ago reporting reduced hospitalization rates among clients in a HPC program [46], while Miccinessi et al. (2003) cited similar findings even for effects of HPC enrollment on readmission time to hospital [17]. Further, Cintron et al. (2003), Lawson et al. (2008), and Brink et al. (2011) cited many other studies reporting similar reasons for ED visits, although they involved different study

populations, including end of life clients not in a HPC program, individuals with a diagnosis of cancer but not at the end of life, and senior populations in general [18, 48, 49].

3.4.3 Temporality

A clear temporal relationship was consistently demonstrated [17, 45, 46, 47, 49]. Studies examined clients who first became terminally ill, enrolled into HPC, and then were followed over time to document ERVH. Temporal gradient was also present in two studies [17, 47]. Constantini et al. (2003) divided their sample into four cohorts depending on the time they entered HPC and reported that the closer to death clients entered HPC the less ERVH were experienced [47]. The reported finding could be due to the fact that those who enrolled closer to death may have had more time to adjust psychologically and emotionally to their fatal illness [18]. Similarly, Miccinessi et al. (2003) reported that the number of ERVH were highest at six months before death compared to three months among those enrolled in HPC [17].

3.4.4 Plausibility

Plausible mechanisms for reduced ERVH among those enrolled in HPC were provided. Constantini et al. (2003) stated that individuals enrolled in HPC may have also been attending cancer centres that would have used more effective treatments to control symptoms [47]. In addition, Cintron et al. (2003) determined that the rate of ERVH was reduced among those enrolled in a HPC program because of better understanding of clients' needs at the end of life, thereby improving provision of HPC and reducing need for hospital management [18]. Further, Cintron et al. (2003) suggested that clients who experienced an ERVH may have still been hoping that their health conditions would improve and therefore decided to withdraw from HPC to receive more aggressive therapies [18].

Pain and respiratory disorders such as dyspnea and chronic obstructive pulmonary disease were cited as major complaints for presenting to the ERVH [18, 23, 24, 48]. As diseases progress, the severity of respiratory conditions also increase and therefore clients visit the ED to improve symptoms and tolerability of the dying process. Pain may also increase as diseases progress, if adequate chronic pain control is not administered at the end of life, and so clients may visit the ED to relieve suffering [48].

3.5 Strength of Evidence

Although the reviewed studies suffered from a few limitations, such as selection bias, information bias, lack definition for HPC, and lack of consideration for client preferences for place of care and client goals, the strengths still outweigh the weaknesses. The studies had great strength in having large sample sizes, good evidence of external validity, and controlling for confounders (e.g., age and gender) which made the associations between the exposure and outcome more valid. In addition, study findings had increased statistical significance, good temporality, consistency, and plausibility.

3.6 Summary

This review supports the hypothesis that HPC is associated with reduced ERVH. The studies reviewed provided strong evidence to demonstrate that there is a clear association between HPC enrolment and reduced ERVH, despite including samples that differed in ethnicity, sociodemographic backgrounds, care settings (i.e., hospice, home, nursing home) and time periods ranging from one year, six months, three months, and one month before death.

In addition, the studies reviewed provided evidence to support an association between contributing factors such as rural residency, co-morbidities (e.g., diabetes), dyspnea, pain, chronic obstructive pulmonary disease, falls/fractures, delirium, fatigue, weight loss,

nausea/vomiting, previous hospitalization with ERVH [18, 23, 24, 48]. Since each study examined populations from different countries, ethnicities, sociodemographic backgrounds, and care settings, a variety of different contributing factors were identified, thereby indicating that different populations have different predispositions to ERVH.

The reviewed studies greatly contribute to knowledge as they not only demonstrate an association between HPC and reduced ERVH but they also provide some of the first data on factors contributing to ERVH. However, the majority of the literature reviewed was from the United States, where hospice care refers to care provided in the home and in a hospice. Therefore, no clear distinction was made between factors associated with ERVH among clients receiving services in a hospice facility and those associated with ERVH among clients receiving services in their home. Most importantly, the United States has different health care provisions, so findings may not apply to HPC clients in Canada.

3.7 Conceptual Framework

The Andersen and Newman model has been used to explain health care utilization, including ED visits among the elderly and the general population. Therefore, this model will be used as a conceptual framework for the basis of this study. Andersen and colleagues have formulated a behavioural model which has dominated the study of health care utilization [65, 66]. The theoretical framework has been used to reveal the relative contribution of different sets of variables, which influences health care utilization by the general population and helps develop policies to promote equitable access. The framework was first developed in the 1960s and has since gone through a few phases. One of the initial models (Figure 1) posited that health service use was determined by an individual's predisposition to use services, factors that enable or impede use of services, and their need for care [65].

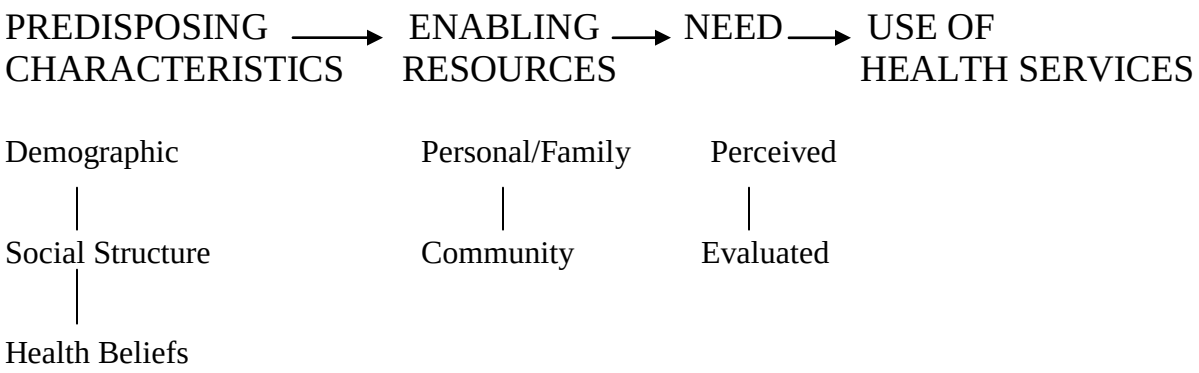

Figure 1. The initial model of the Andersen-Newman framework for health service utilization (1960s). Adapted from "Revising the behavioural Model and Access to Medical Care: does it matter?" by R.M. Andersen, 1995, *Journal of Health and Social Behaviour,* 36, p2.

A modified version of the model (Figure 2) elaborated on the health care system, including national health policy, the resources, and the organization [65]. In addition, there was an emphasis the importance of the measures of health services' use, including the type, site, purpose, and time interval at which the coordinated services were received. Finally, the model also included consumer satisfaction as an outcome of the health services.

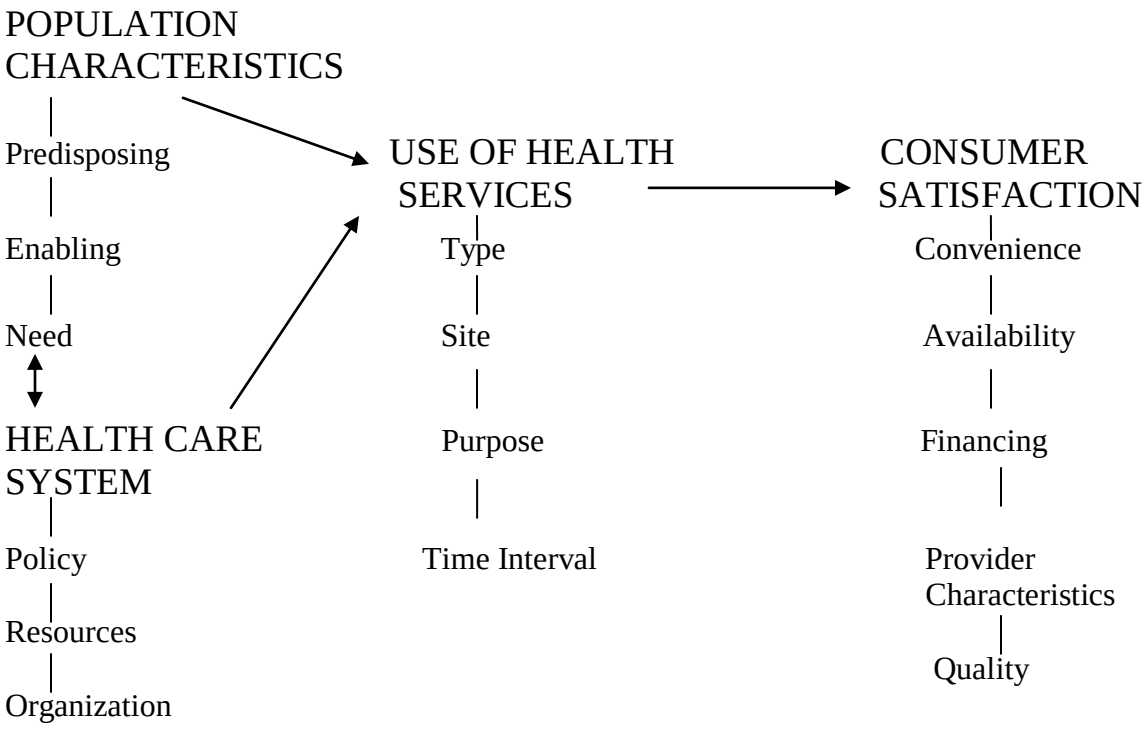

Figure 2. The initial model of the Andersen-Newman framework for health service utilization (1970s). Adapted from "Revising the behavioural Model and Access to Medical Care: does it matter?" by R.M. Andersen, 1995, *Journal of Health and Social Behaviour,* 36, p6.

One of the more recent models (Figure 3) has recognized the importance of including the ability to improve the health status of the population, both as perceived by the population and evaluated by professionals [65]. In addition, this version acknowledges the external environment, which includes the physical, political, and economic components, and personal health practices such as diet, exercise, and self-care [65].

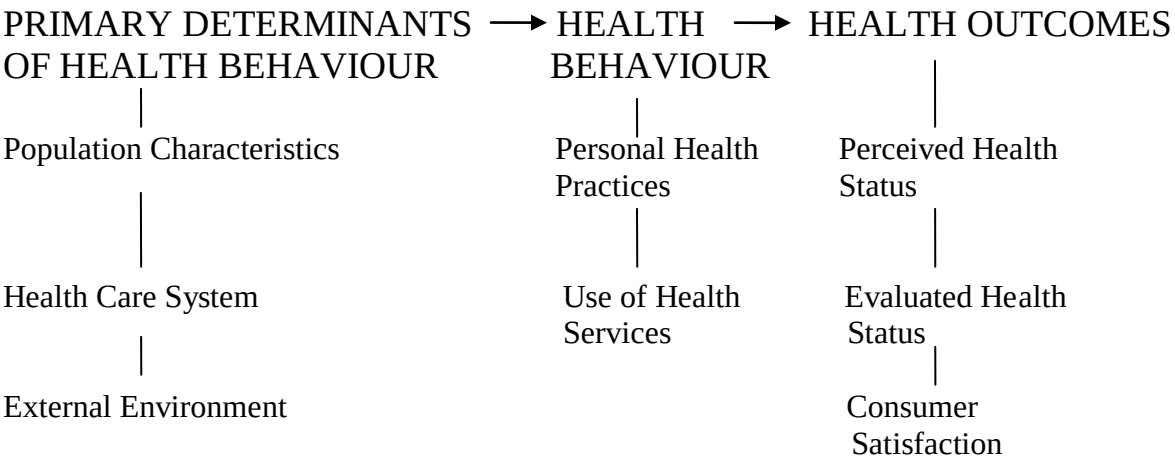

Figure 3. The initial model of the Andersen-Newman framework for health service utilization (1990s). Adapted from "Revising the behavioural Model and Access to Medical Care: does it matter?" by R.M. Andersen, 1995, *Journal of Health and Social Behaviour,* 36, p7.

Although the behavioural model has gone through many changes over the years, the population characteristics which are also known as the individual determinants have continuously remained in the model. The individual determinants, the focus of this present research, are grouped into three domains (Figure 4). The model puts forward that health behaviours, such as emergency department visits, are a function of predisposing characteristics: the individual's predisposition to use services, enabling factors: the ability to use services, and need variables: perceived and evaluated illness [66]. Predisposing characteristics represent individual characteristics which exist prior to the illness and may result in individuals having a higher propensity towards use services. Predisposing characteristics include demographic factors such as age and gender; social-structural factors such as living conditions, social environment of the individual, and the behaviour patterns; as well as attitudes and beliefs related to the use of health services [66]. Enabling factors are conditions that make health services available (health personnel and facilities), accessible (urban versus rural) and affordable (health insurance) [66]. The need component reflect illness levels that require service use. The need factors represent a perceived illness of sufficient magnitude to seek care or an evaluated illness to determine the severity and need for care, which must be present in order for service use to take place [66, 67].

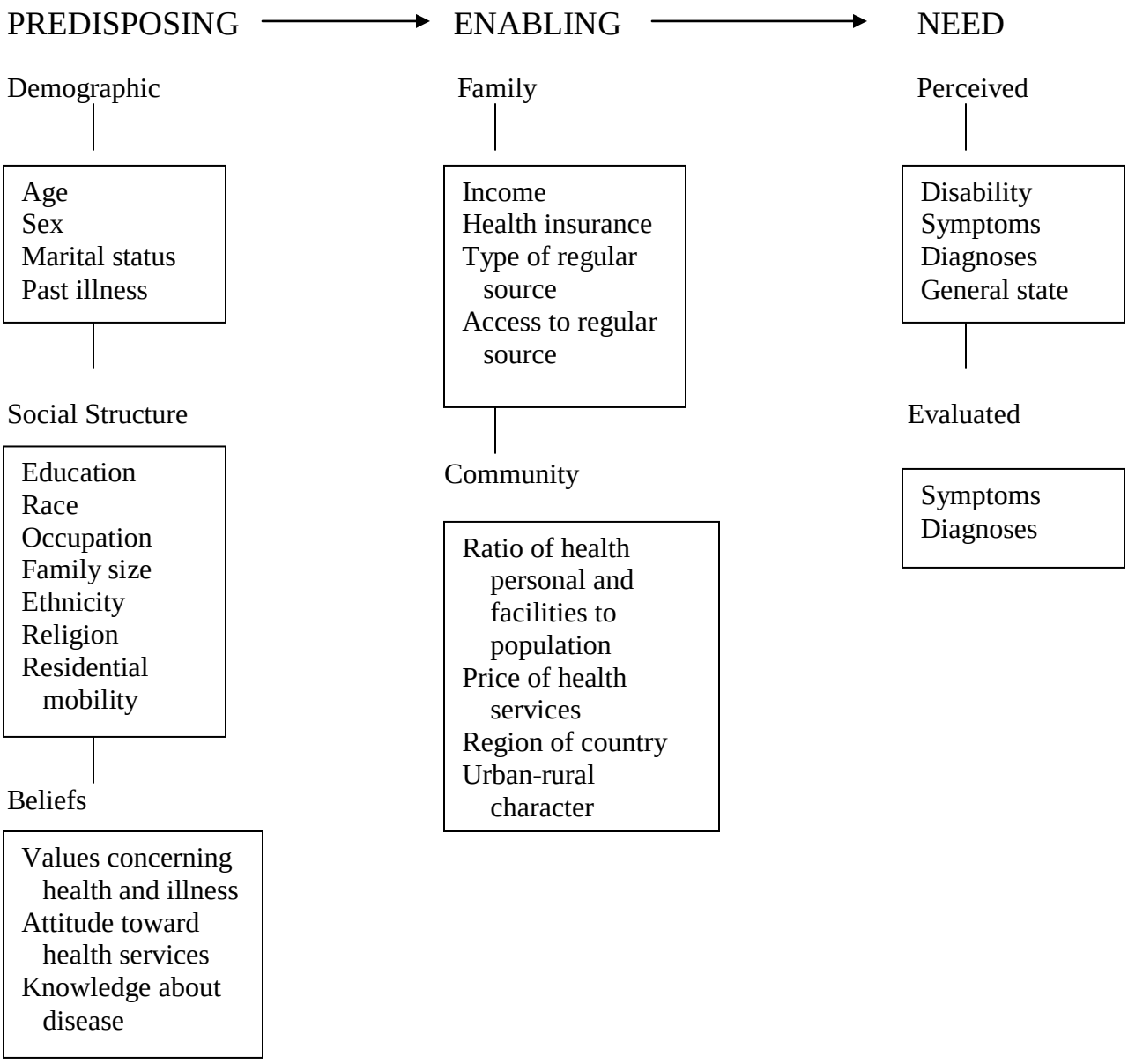

Figure 4. The Andersen-Newman framework: Individual determinants of health service utilization. Adapted from "Societal and Individual Determinants of Medical Care Utilization in the United States," by R. M. Andersen and J.F. Newman, 1973, *Health and Society*, 51, p107.

The conceptual model has been frequently employed to explain variation in use of ERVH among older adult populations as shown in Appendix D. The studies have applied the framework to determine health service utilization, specifically physician visits, ED visits, and hospital admissions. The studies examined are characterized by a high degree of heterogeneity with respect to year of study conduct, country, study settings, patient samples, health care utilization measures, the instruments used, the procedures followed, the research methodologies, and the statistical tests that have been employed.

Despite the heterogeneity, the results were similar. Twelve out of the 14 studies have determined predisposing characteristics as having a moderate effect, enabling factors as being the most distal cause of health service use, while need-based variables as the most proximate [68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79]. Need, both perceived and evaluated, appears to be the primary determinant of ED visits and hospitalizations among older adults. Perceived health status was a consistent predictor of ERVH in 9 of the 14 studies. Measures of evaluated health status were also consistent predictors, which included activities of daily living deficiencies, physical function status, and acute illnesses. In the two studies where predisposing characteristics and enabling factors explained great variance in utilization, there was inequitable access to services. Parboosing et al. (1987) reported that 53% of the sample attempted to contact their family physician but less than one third had succeeded [67]. Shibusawa et al. (2010) reported that Medicare enrolment was associated with ERVH but majority of patients were not enrolled [80]. Therefore, in studies where samples have equitable access, need should be the most accurate predictor of ERVH [81].

The Andersen-Newman framework is considered a suitable conceptual model for the basis of this research because a) the framework was established specifically for examining

determinants of hospital use; b) it helps to relate individual determinants to hospital utilization in a rational fashion; c) it helps to guide the selection of variables to include in the analysis; and d) research has successfully utilized the framework to reveal variables that contribute to hospitalization among older adults.

Chapter 4

Study Rationale

An understanding can be gained of how often ERVH occur among palliative home care clients within their last months of life, and the differences in characteristics between those who have an ERVH and those who do not. Further, recognition of variables most important in explaining and predicting ERVH would make it possible to identify clients at risk of avoidable hospitalizations and assist in care planning. Potentially avoidable hospitalizations have been defined as hospitalizations among individuals who are dying, which seem to be avoidable in an optimally functioning home care program [82]. Although not all ERVH are avoidable, fewer would be needed if palliative home care services provided high quality care.

The limited number of articles available for review indicates that the area of ERVH, specifically among palliative home care clients, has received very little attention. The majority of the studies reviewed were American and a few were from Italy and so their findings may not be relevant to Ontario due to differences in culture and healthcare organization. Only two Canadian studies were available for review. Lawson et al. (2008) examined palliative home care clients in conjunction with clients in long-term care and palliative care units; thereby not differentiating findings between the three client types [48]. Although Brink et al. (2011) examined palliative home care clients, the researchers only examined ED use without also considering hospital admissions [49]. In addition, the study suffered from a few limitations, including a small sample size (n=93) that may have led to a type II error; findings can only be generalized to clients with cancer; length of time spent in the palliative program was not discussed; and time and day of ED visits were not analysed.

4.1 Purpose, Goals & Objectives

The purpose of this study is to address the limitations of previous studies outlined above. This study will identify variables most important in explaining and predicting ERVH prior to death among palliative home care clients, using the Andersen-Newman framework for health service utilization. To our knowledge, studies have yet to use the Andersen-Newman framework among a HPC population.

The specific objectives of this research are to determine: a) whether the predisposing, enabling, and need variables are associated with ERVH, and b) which types of determinants best explains and predicts ERVH. The goals of this research are to determine: 1) whether the factors can be used to identify clients at risk of ERVH, and 2) whether the main factors related to ERVH are avoidable.

4.2 Research Questions

The following questions will be addressed in this research:

1. What are the profiles of HPC clients who experience ERVH?
2. What are the associations of the predisposing, enabling, need variables with ERVH?
3. What level(s) of the framework will be most important in predicting ERVH?

4.3 Relevance of Research

An understanding of risk factors associated with ERVH among palliative home care clients can help inform decisions related to health policy and service delivery. Such knowledge could help HPC service providers identify clients at risk of avoidable ERVH and focus services on treating factors for which the organizations are well equipped. Policymakers, managers of HPC programmes, and others committed to the improvement of end of life care could also

benefit as this research may provide insight into the effectiveness of care delivered, identify areas in need of improvement, and initiate strategies to modify services and practices to better support clients.

Identification of risk factors that are modifiable may require client and caregiver behaviour change, health provider behaviour change, and health system policy change. In contrast, identification of non-modifiable risk factors can be used to identify clients at greatest risk for ERVH and for risk adjustment when comparing across individuals and jurisdictions.

Chapter 5

Methods

5.1 Ethics Approval

Full ethics approval for this study was granted from the University of Waterloo Office of Research Ethics (Appendix E). Hamilton Niagara Haldimand Brant (HNHB) Community Care Access Centre (CCAC) also approved use of client data for research purposes (Appendix F) and accepted the University of Waterloo's ethics clearance. Written consent was also received from clients to share their personal health information (Appendix G).

5.2 Design and Setting

This study was a retrospective cohort study, designed to examine potential predictors of unplanned emergency room visits or acute hospital admissions or both among palliative home care clients. The study was conducted with a sample of 764 clients, who received palliative home care services from the Hamilton branch of the HNHB CCAC in Ontario, Canada.

5.3 Comparison of Community Care Access Centres

To ensure that HNHB is comparable to the other 13 CCACs in terms of number of clients admitted, number of clients serviced, and total expenses, data from 2009 to 2010 was obtained from the MOHLTC website. Data were also retrieved from the Census Canada website; however, 2006 data were used because 2011 data was not yet available. Comparisons of all CCACs are shown in Tables 1, 2, 3 and 4.

Table 1 shows the number of acute, rehab, maintenance, long term supportive, and end of life clients admitted in April 2009 to July 2010. Acute clients had the highest number of

admissions, while end of life clients had the lowest. HNHB admitted the highest number of end of life clients and the highest number of overall admissions.

Table 1 *CCAC 2009/2010 Year End Report: Admissions by Service Recipient and Age Category*

LHIN Name	Acute		Rehab		Maintenance		Long Term Supportive		End of Life		Total Admissions
	Elderly 65+	Adult 18-64	Elderly 65+	Adult 18-64	Elderly 65+	Adult 18-64	Elderly 65+	Adult 18-64	Elderly 65+	Adult 18-64	
HAMILTON NIAGARA HALDIMAND BRANT	9,075	10,311	6,847	2,578	6,556	1,690	1,536	253	1,064	493	40,403
CENTRAL EAST	6,547	8,968	5,883	2,776	5,082	1,250	1,521	145	768	447	33,387
CENTRAL	5,334	7,575	5,175	1,886	5,926	1,720	696	118	451	211	29,092
TORONTO CENTRAL	4,739	5,958	2,245	1,229	4,062	1,491	1,772	403	451	223	22,573
CHAMPLAIN	4,808	7,676	3,021	1,155	4,923	1,803	1,733	339	724	344	26,526
SOUTH WEST	7,321	8,614	5,531	2,568	4,413	1,115	1,195	257	312	141	31,467
MISSISSAUGA HALTON	5,928	6,788	1,636	545	3,851	812	404	72	540	213	20,789
ERIE ST. CLAIR	6,692	6,867	2,741	1,117	1,833	623	507	139	286	123	20,928
NORTH EAST	3,308	4,505	2,607	1,190	2,568	704	730	192	425	215	16,444
SOUTH EAST	3,274	3,038	2,850	1,281	1,959	567	696	123	251	93	14,132
WATERLOO WELLINGTON	2,882	4,367	3,938	1,719	2,721	364	787	76	561	295	17,710
CENTRAL WEST	1,570	4,014	2,691	1,313	2,215	1,003	280	130	154	57	13,427
NORTH SIMCOE MUSKOKA	1,609	2,287	808	400	2,928	1,071	695	158	163	62	10,181
NORTH WEST	1,440	1,474	1,020	462	925	272	224	32	84	45	5,978
Provincial Total	64,527	82,442	46,993	20,219	49,962	14,485	12,776	2,437	6,234	2,962	303,037

A comparison of the number of end of life clients who received services from all CCACs within the one year period is shown in Table 2. HNHB and many other CCACs served similar percentages of end of life clients, ranging from 3% to 5%.

Table 2 *CCAC 20099/2010 Year End Report: Number of Individuals Served*

LHIN/CCAC Name	End of Life Adult 18 to 64	End of Life Elderly 65+	In-Home Health Care (includes end of life)	All Programs (In-Home Health Care, Publicly Funded Schools, Private/In-Home Schools, LTC Placement)	Of Individuals in All Programs: Proportion of Clients in a Palliative Caseload (%)
HAMILTON NIAGARA HALDIMAND BRANT	823	1,956	61,484	72,450	3.8
CENTRAL EAST	810	1,842	53,138	70,062	3.8
CENTRAL	605	1,399	51,271	65,199	3.1
TORONTO CENTRAL	891	1,540	45,527	55,755	4.4
CHAMPLAIN	858	1,673	43,617	52,236	4.8
SOUTH WEST	437	943	49,409	56,551	2.4
MISSISSAUGA HALTON	452	1,049	34,415	41,115	3.6
ERIE ST. CLAIR	407	984	29,302	33,945	4.1
NORTH EAST	387	895	26,869	32,882	3.9
SOUTH EAST	251	663	22,617	27,294	3.3
WATERLOO WELLINGTON	579	1,118	29,210	34,265	4.9
CENTRAL WEST	175	379	22,481	28,184	2.0
NORTH SIMCOE MUSKOKA	244	654	17,096	21,420	4.2
NORTH WEST	97	224	9,699	12,177	2.6
Provincial Total	7,016	15,319	496,135	603,535	3.7

Table 3 shows that, although HNHB admitted and served the most end of life clients and the most clients overall, its average expense per home care client and its total expenses were still similar to those of the other CCACs.

Table 3 *CCAC 20099/2010 Year End Report: Expenses*

LHIN/CCAC Name	Average Expenses per In-Home Health Care Client	Total In-Home Health Support Services	Total Client Services	Total Expenses
HAMILTON NIAGARA HALDIMAND BRANT	$3,473.63	$75,737,706	$213,572,624	$232,333,133
CENTRAL EAST	$3,671.47	$66,032,133	$195,094,385	$216,519,179
CENTRAL	$3,741.34	$70,362,149	$191,822,365	$208,892,780
TORONTO CENTRAL	$3,639.22	$62,230,578	$165,682,624	$182,391,687
CHAMPLAIN	$3,831.25	$59,279,956	$167,107,832	$183,177,272
SOUTH WEST	$3,090.14	$48,716,266	$152,680,674	$169,630,528
MISSISSAUGA HALTON	$3,031.62	$38,968,977	$104,333,102	$116,020,646
ERIE ST. CLAIR	$3,198.10	$28,418,895	$93,710,587	$102,642,660
NORTH EAST	$3,409.19	$29,741,387	$91,601,537	$102,587,349
SOUTH EAST	$3,767.81	$29,767,351	$85,216,515	$94,687,943
WATERLOO WELLINGTON	$2,937.37	$27,246,283	$85,800,464	$95,575,849
CENTRAL WEST	$2,941.39	$21,520,813	$66,125,423	$75,819,934
NORTH SIMCOE MUSKOKA	$3,671.51	$18,584,504	$62,768,182	$70,253,875
NORTH WEST	$3,465.83	$12,240,262	$33,615,108	$38,088,036
Provincial Total	$3,444.89	588,847,260	$1,709,131,422	$1,888,620,871

Further, as shown in Table 4, although HNHB served a larger total number of clients than other CCACs, the region still served roughly the same estimated proportion of individuals as the other CCACs (between 4% and 6%).

Table 4 *Estimated Proportion of Population Served by Each CCAC in 2009/2010*

LHIN Name	2006 Census: Population Aged 65+	2006 Census: Total Population	Population Density per Square Kilometre	CCAC: Individuals Served in All Programs	Estimated Proportion of Population Served (%)
HAMILTON NIAGARA HALDIMAND BRANT	208,060	1,315,964	203.3	72,450	5.5
CENTRAL EAST	196,300	1,432,695	93.8	70,062	4.9
CENTRAL	192,215	1,532,649	561.30	65,199	4.3
TORONTO CENTRAL	141,360	1,090,301	5,679.0	55,755	5.1
CHAMPLAIN	151,925	1,147,209	65.1	52,236	4.6
SOUTH WEST	136,740	901,123	43.1	56,551	6.3
MISSISSAUGA HALTON	109,950	1,008,004	956.7	41,115	4.1
ERIE ST. CLAIR	91,380	630,195	86.1	33,945	5.4
NORTH EAST	91,000	551,691	1.4	32,882	6.0
SOUTH EAST	80,405	466,669	26.1	27,294	5.8
WATERLOO WELLINGTON	82,685	686,324	144.6	34,265	5.0
CENTRAL WEST	69,665	739,957	285.7	28,184	3.8
NORTH SIMCOE MUSKOKA	64,315	422,902	50.5	21,420	5.1
NORTH WEST	33,180	234,599	0.6	12,177	5.2
Provincial Total	1,649,180	12,160,282	13.4	603,535	5.0

The above comparisons indicate that HNHB is comparable to other CCACs in terms of percentage of end of life clients receiving services and average expenses.

The 2006 population census was also used to compare the socioeconomic status of individuals living within the HNHB region to that of all individuals living in the province of Ontario and in Canada. Table 5 shows that the socioeconomic status of individuals living within the HNHB region is very comparable to that of individuals living in Ontario and in Canada. However, there was one major difference in terms of HNHB having a low percentage of visible minority residents.

Table 5 *Census 2006 Data: Socioeconomic Comparison*

Population Characteristics	**HNHB % (n)**	**Ontario % (n)**	**Canada % (n)**
Age	N=1,315,970	N=12,160,285	N=31,612,895
0-19	24.5 (322,165)	25.0 (3,043,930)	24.4 (7,720,325)
20-64	59.7 (785,750)	61.4 (7,467,195)	61.9 (19,557,305)
65+	15.8 (208,060)	13.6 (1,649,180)	13.7 (4,335,250)
Gender	N=1,315,970	N=12,160,285	N=31,612,895
Male	48.5 (639,000)	48.8 (5,930,700)	48.9 (15,475,970)
Female	51.4 (676,970)	51.8 (6,229,580)	51.1 (16,136,930)
Legal Marital Status (15 years and over)	N=1,084,210	N=9,949,480	N=26,033,060
Married	51.7 (560,990)	51.9 (5,168,660)	47.9 (12,470,400)
Other	48.2 (523,220)	48.1 (4,780,820)	52.1 (13,562,660)
Mother Tongue	N=1,298,270	N=12,028,900	N=31,241,030
English Only	79.2 (1,027,990)	68.4 (8,230,705)	57.3 (17,882,780)
English & French	0.2 (2360)	0.3 (32,685)	0.3 (98,630)
Other	20.6 (267,920)	31.3 (3,765,510)	42.4 (13,259,620)
Visible Minority	N=1,298,270	N=12,028,895	N=31,241,030
Yes	9.1 (118,140)	22.8 (2,745,200)	16.2 (5,068,095)
Educational Attainment (15 years and over)	N = 1,066,665	N=9,819,420	N=25,664,220
High School Diploma	28.3 (301,535)	26.8 (2,628,575)	25.4 (6,553,425)
Apprenticeship or Trades	9.4 (100,655)	8.0 (785,115)	10.8 (2,785,420)
College Diploma	20.2 (215,860)	18.4 (1,804,775)	17.3 (4,435,135)
University Certificate, Diploma or Degree	14.8 (158,135)	20.5 (2,012,060)	18.1 (4,655,770)
Labour force activity (15 years and over)	N=1,066,665	N=9,819,420	N=25,664,220
Employment rate	61.7 (658,365)	62.8 (6,164,245)	62.4 (16,021,180)
Unemployment rate	6.0	6.4	6.6
Income in 2005	N=1,022,155	N=9,340,020	N=24,423,165

Median Income -Persons 15 years and over	$27,006	$27,258	$25,615
Median Income After Tax - Persons 15 years and over	$24,376	$24,604	$23,307

5.4 Data Source

The source of data used for the analyses is a standardized assessment instrument called the interRAI for Palliative Care (interRAI PC) (Appendix H). The instrument was developed by an international group of researchers called interRAI and is part of an integrated suite of assessment systems used in many countries throughout the world [83]. The standardized instrument was developed to assess care needs of palliative clients in a home care setting. The organization also developed instruments for use among other populations, such as clients in long term care and complex continuing care. The instruments were designed to be integrated, thereby improving the continuity of care across multiple care settings [83]. The interRAI PC is used to evaluate needs, strengths and preferences of adult clients (18 years of age and older) in palliative care settings. The assessment includes basic demographic information and covers various domains including cognitive and physical functioning, mood, health conditions and service utilization. It facilitates collection of accurate person-specific data, thus allowing for a comprehensive understanding of clients' palliative care needs. It also identifies areas of care that require further attention and contributes to ongoing care planning [84]. Case managers gather information from available sources including clients, family members, and caregivers, and they use their clinical judgement to code items in the case of confidential information from these sources. All CCACs in Ontario, except for one, have adopted the interRAI PC. Having access to such reliable and valid information allows for better data analysis, which ultimately provides answers for care planning, outcome measures, quality improvement, and resource allocation.

5.4.1 Reliability

Researchers from 12 countries tested inter-rater reliability of the instrument in long term care facilities, home care, palliative care, post-acute care, and mental health [83]. The overall kappa

for 161 items, common to two or more instruments, was 0.75 indicating excellent reliability. For items that were unique to the palliative instrument, the kappa was 0.63 [83]. Further, the interRAI PC assessment was tested in 3 countries and in more than 5 types of care settings. The assessment provided evidence of good reliability, with about 50% of the assessment items having kappa values of 0.8 or higher [84], and the average kappa values for the different domains ranged from 0.76 to 0.96. Therefore, researchers determined that the interRAI instruments can be considered to have substantial overall reliability [83].

5.4.2 Validity

The interRAI instruments have been proven to be valid, displaying good face validity and content validity, indicating that the instruments do measure what they are intended to [86]. In addition, the instruments have also been proven to have good predictive validity, indicating their ability to predict subsequent functioning among older adults [85].

5.5 Scales

There are several embedded scales available within the interRAI PC. The scales used in these analyses are the Activities of Daily Living Hierarchy scale (ADLH) that assesses basic independent living skills, the Changes in Health End stage disease and Signs and Symptoms scale (CHESS) that predicts mortality and instability in health, and the Pain scale that measures frequency and severity of pain.

The ADLH scale is a hierarchical algorithm based on items such as eating, personal hygiene, toileting, and locomotion within the home. Each item has 7 response scales: 0 independent, 1 supervision needed, 2 limited supervision needed, 3 extensive assistance needed-1, 4 extensive assistance needed-2, 5 dependent, 6 complete dependence. Previous research has determined the scale to be valid, with a validity coefficient ranging from r=.58 to r-=.79 [86].

Reliability of the scale was also proven with a Pearson Correlation of r=0.61 and Kappa = 0.97 [87].

The CHESS scale uses assessment items from the interRAI PC such as weight loss, shortness of breath, vomiting, dehydration, leaving food uneaten, and peripheral edema. The scale takes on values of 0 (no symptoms), 1 (at least one symptom), or 2 (two or more symptoms). An additional score of 1 is added for each of the following items: end stage disease, decline in cognitive and ADL function, with the final scale ranging from 0 (stable health) to 5 (increased frailty and health instability). The scale has been validated, as it has been determined to be highly predictive of mortality [86, 87].

The Pain scale is comprised of 2 items measuring frequency and intensity of pain. Pain frequency responses include: 0 pain not present, 1 present but not exhibited in last 3 days, 2 exhibited on 1 of 2 days, 3 exhibited daily in the last 3 days. Pain intensity response include: 0 no pain, 1 mild pain, 2 moderate pain, 3 severe pain, and 4 excruciating pain. The scale has been validated against the Visual Analogue Scale for pain [88].

5.6 Databases

The database for the interRAI PC assessments was merged with 3 other databases based on client ID: the CCAC client database Client Health Related Information System (CHRIS), and the Canadian Institute for Health Information databases including the National Ambulatory Care Reporting System (NACRS) and Discharge Abstract Database (DAD), which facilitate the collection of standardized information on hospital patients. CHRIS provides information on palliative care program enrolment date, interRAI PC assessment date, discharge date, client service utilization, service costs, death date, and physician access information. The NACRS

database contains information for hospital-based and community-based emergency and ambulatory care, which includes date and time of ED visits, admit date, discharge date, and admit category (i.e., day surgery, outpatient clinic). The DAD database is used to document hospital admissions, which includes information on admit date, discharge date, and diagnoses (i.e., pneumonia and urinary tract infection) associated with the admission.

Measures were taken to validate information presented in the databases. The DAD hospital admission information was validated against the CCAC CHRIS database which puts client cases on hold when they are informed of an ERVH. Therefore there were no data quality issues with the data linkage or DAD database, which increases confidence that there were no false positive or negative cases of hospital admissions. Further, in order to ensure integrity of the data, items in the interRAI PC assessment forms were examined against the information scanned into the database to ensure that the output coding was also correct.

5.7 Privacy & Confidentiality

To ensure clients' privacy and confidentiality, all client identifier information was removed from the linked data. Paper records of the interRAI PC were kept in a secure storage at the School of Public Health and Health Systems, University of Waterloo. Electronic versions of the interRAI PC were stored on a secure network at the University of Waterloo. Access was restricted to authorized individuals bound under a privacy agreement (Appendix I).

5.8 Datacut

Individuals whose health conditions are not responsive to curative treatment, who require alleviation of distressing symptoms to improve quality of life, and who have a prognosis of six months or less are placed on a palliative caseload. Once placed on a palliative caseload, clients receive an initial assessment within 45 days of service, six months, and yearly thereafter. If there

are significant changes in a clients' condition, additional assessments may be conducted. The anonymized datacut used for the analyses includes client information for clients who received services from the Hamilton branch of the HNHB CCAC, from April 2008 to July 2010. Access was only given to administrative data and DAD/NACRS data for clients who received services from the Hamilton branch of the HNHB CCAC. Also, the specific time period was chosen because acute discharges by Hamilton CCAC clients could only be matched to DAD/NACRS databases starting in April 2008, and no other interRAI PC assessments were scanned into the database after July 2010, as the Hamilton branch was piloting electronic versions.

5.9 Analytic Sample

To create the analytic sample, specific criteria had to be met: (1) clients at least 18 years of age, (2) with any terminal illness, (3) who had an informal caregiver (4) who may have had other conditions (e.g., renal failure, hypertension, diabetes), and (5) who died within one year or less of the interRAI PC in order for assessment information to remain relevant. Clients who had a prognosis of six months or less but were on service for longer than one year were excluded because they might differ from the rest of the palliative population who generally die within a few months of being placed on a palliative caseload. A final sample of 764 clients was included in this study (Figure 5).

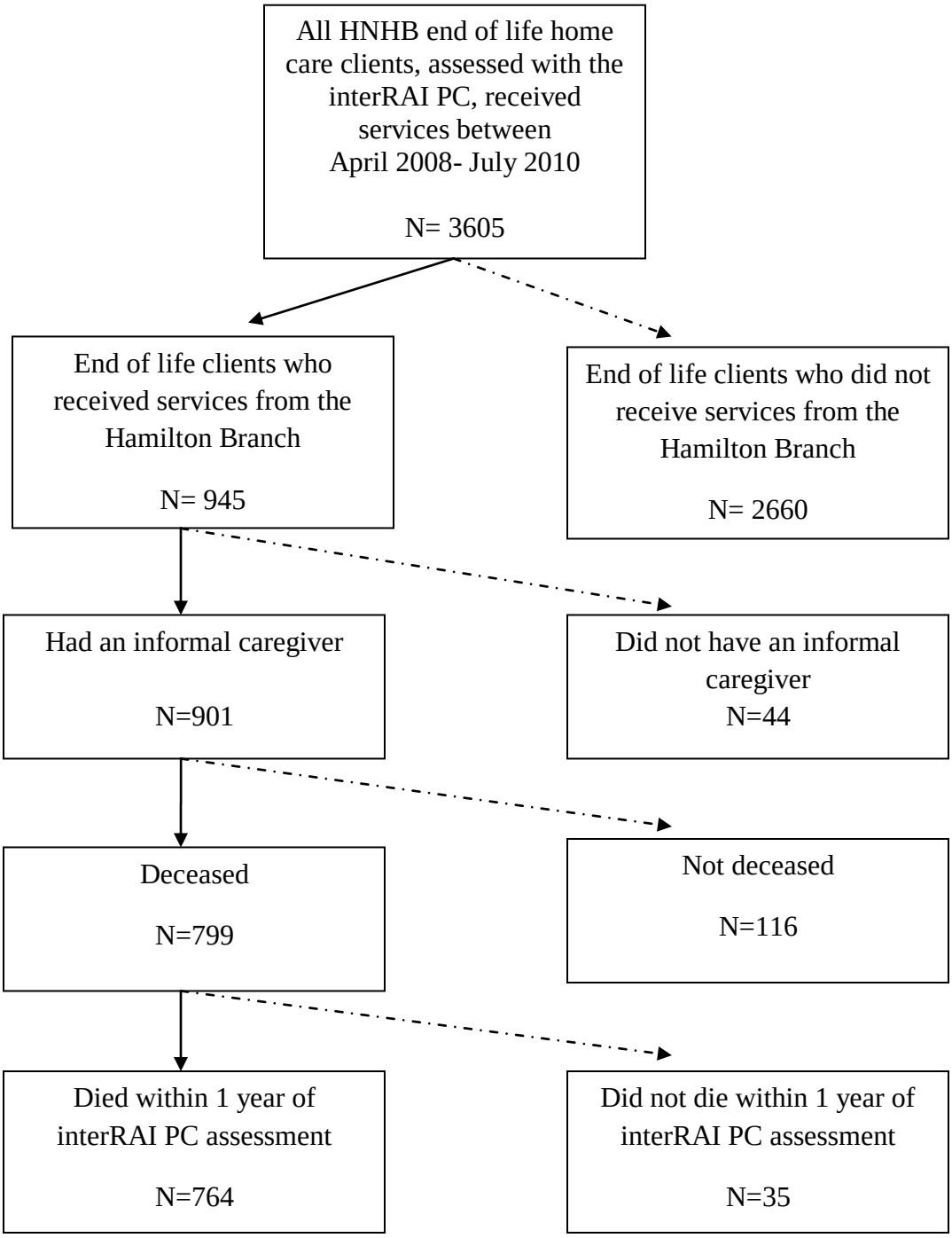

Figure 5. Flow diagram of the study sample.

5.10 Independent Variables

Most of the independent variables used in the analyses are from the interRAI PC assessment with the exception of a few variables retrieved from CHRIS, DAD, and NACRS. Independent variables were identified through the literature review discussed in Chapter 3 and additional variables were included for exploratory reasons. Most variables were collapsed into binary variables and categorized into predisposing, enabling, and need variables.

Predisposing variables that were used included sex (a2), age (a3a,b,c), marital status (a4), finds guidance in religion or spirituality (i2a), wish to die at home (n3a), wish to die now (n3c), and advance directives (do not resuscitate (n2a), do not intubate (n2b), do not hospitalize (n2c), do not send to emergency department (n2d), do not tube feed (n2e), medication restriction (n2f)).

Enabling variables included health insurance coverage (a7a), caregiver distress (caregiver feelings of distress, anger, or depression (o4c) and feeling as though they were unable to continue caring activities (o4b)), and rural character ((a14) a zero in the second position of the postal code is used to identify rural character in Canada)) [89]. Access to physician services, and median cost of care were retrieved from the CHRIS database. Clients' cost of care (above or below median) was derived using cost of formal services the week prior to interRAI PC assessment and two weeks following the assessment, for clients who did not pass away and who did not have an ERVH within that period. If cost of clients who passed away or had an ERVH during those 3 weeks would have been included, the median cost of care would have been inaccurate. The cost of care for those clients would have been $0, when in fact they would have probably incurred costs if they were on service.

Need variables included previous hospitalizations (a17), dyspnea (c2), fatigue (c3), falls (c4), constipation (c5d), nausea (c5g), vomiting (c5h), dizziness (c5k), peripheral edema (c5s), weight loss of 5% or more in last 30 days or 10% or more in last 180 days (d2a), modification needed to swallow (d3), cognitive skills for daily decision making (f1), potential delirium (f4a or f4b or f4c), pressure ulcers (e1), self-rated depressed mood (h2a or h2b or h2c), instrumental activities of daily living (j1a, j1b, j1c), person believes he/she is capable of improved performance in physical function (j4a), bladder and bowel incontinence (k1, k2), Pain Scale, ADLH, and CHESS. Although the interRAI PC also has other scales embedded within it, such as the Cognitive Performance Scale (CPS) that measures an individual's cognitive skills, and the Depression Rating Scale (DRS) that indicates possible depression, they could not be used as need variables due to an increased number of missing values.

Assessors used their best clinical judgement to code diagnoses using the most accurate, reliable, and valid information source available. The following diagnoses were also included (a10): cancer, circulatory system diseases (cerebrovascular accident, congestive heart failure, coronary artery disease, hypertension, hypotension, deep vein thrombosis), respiratory system diseases (chronic obstructive pulmonary disease, emphysema, asthma, respiratory infection), neurological diseases (Alzheimer's, dementia, multiple sclerosis, amyotrophic lateral sclerosis), digestive disorders (liver disease, gastrointestinal disease), and diabetes. Although the interRAI PC has a section to document clients' disease diagnoses, it does not have enough granularity for infections. Therefore, pneumonia and urinary tract infections were retrieved from the NACRS and DAD databases. In order for the infections to remain relevant, only those resulting in a hospital visit up to one month prior to the interRAI PC assessment were included. Both infections were considered as a marker for a client's general state because they may have been

related to the impaired immune function, anatomic and functional changes accompanying the client's terminal illness.

Emergency room visits and acute hospital admissions information were retrieved from the NACRS and DAD databases. Only emergency department visits coded as urgent rather than elective were included. Both were compiled into binary variables, with the dependent variable coded as true if ERVH was documented.

5.11 Missing Values

A few interRAI PC items were excluded due to missing values. All data were entered into paper forms since the interRAI PC was not yet computer based. Therefore, it was not possible to do automated computer checks for completeness. Missing values must be addressed as they may result in bias and cause difficulties in interpreting results. Variables that had a high number of missing values (60 or more) were completely discarded. Such variables included living status, awareness of prognosis, hallucinations, fever, consciousness, dehydration, cognitive performance scale, and depression rating scale. When items had less than 60 missing values, a different approach was taken. Since most variables were binary, missing values were re-coded with the response of (0) as to not over-estimate presence of potential predictors and to protect against loss of sample size. This approach was taken for the following variables: finds guidance in religion, wish to die at home, wish to die now, any advance directives, caregiver feelings of distress or unable to continue caring activities, believes his/her physical function can improve, and weight loss. There was a moderate number of missing data for the previous hospitalizations item in the interRAI PC, so data from the DAD database were used to re-code previous hospitalizations.

5.12 Statistical Analyses

All statistical analyses were performed using SAS statistical software version 9.2. Analyses were conducted using information from all palliative home care clients described in the analytic sample. The dependent variable was ERVH, with documentation of an event as the reference group.

Bivariate analyses were conducted using frequencies, percentages, means, and chi-square tests. The analyses were performed to examine the relationship between client characteristics and one or more ERVH.

Multivariate regression analyses were performed to identify potential predictors of ERVH using binary logistic regression. Logistic regression models were derived using all statistically significant (α=0.05) variables associated with the dependent variable in the bivariate analyses. Four separate logistic regression models were tested, 1) predisposing only, 2) enabling only, 3) need only, and 4) predisposing, enabling, and need combined. Automatic model selection, including forward selection, backward elimination, and stepwise were used initially to get an appreciation of possible models. However, all variables were entered into the relevant categories using manual backward selection to determine best fitted models. In this method, explanatory variables were entered in a single step, and then systematically eliminated one at a time from each model according to p-values of less than 0.05 until only significant variables were left in the models. Some non-significant variables were also examined as possible predictors in the logistic regression analyses if further consideration was warranted based on the literature review.
In addition, theoretically relevant interaction effects of several independent variables were examined: age group and wish to die at home, age group and having directives, sex and marital

status, sex and prior urinary tract infection, ADLH and prior pneumonia, and ADLH and prior urinary tract infection.

The fourth model combining the predisposing, enabling, and need variables was stratified by time to death in order to examine whether proximity to death would result in a different model: a median of 46 days or less from interRAI PC assessment to death versus more than 46 days.

Past studies, that have used the Andersen-Newman framework for health service utilization to determine predictors of ERVH among older adult populations, have determined need based variables as the most proximate cause of hospital use and predisposing characteristics and enabling factors as being more distal causes. In order to test this finding, the final model was stratified by need level (CHESS score of 2+, ADLH of 1+, swallowing difficulties, bladder or bowel incontinence, dizziness, and difficulty with daily decision making including delirium) of 0 symptoms versus 1 or more versus 2 or more.

Logistic regression does not utilize information regarding the point in time during which the event (i.e., ERVH) occurred, thereby giving an ERVH which occurred near the beginning of the follow-up period (from interRAI PC assessment to death) the same weight in the analysis as one that occurred closer to death. Therefore, survival analysis (or time to event analysis) was performed to identify factors that have a significant effect on the hazard rate of when ERVH occurred. Survival was measured as time in days from interRAI PC assessment date to date at which an event occurred. Clients were right-censored at time of the event; if no events occurred then clients were censored at death. All deaths occurred up to 365 days after interRAI PC assessment. Three dependent variables/events were tested a) emergency room visits, b) acute

hospital admissions, and c) emergency room visits or acute hospital admissions. Also four separate models were tested for each dependent variable 1) predisposing only, 2) enabling only, 3) need only, and 4) predisposing, enabling, and need combined.

Kaplan-Meier was conducted to determine whether the predictive variables were proportional (e.g., whether the time to event is approximately parallel for those who are married vs. not married) and based on these findings all predictors with a p-value of 0.25 or less were entered into the Cox proportional hazards regression. All predictors were entered into the regression in a single step and a probability of p=0.05 was used to determine which predictors were kept in the 4 models for each dependent variable. Interactions of the independent variables with time were examined since one of the main assumptions of the Cox regression is proportionality, when a time-dependent covariate is significant it indicates a violation of the proportionality assumption; however, none of the variables interacted with time.

The fourth model combining the predisposing, enabling, and need variables was stratified for all 3 dependent variables by need level (CHESS score of 2+, ADLH of 1+, swallowing difficulties, bladder or bowel incontinence, dizziness, and difficulty with daily decision making including delirium) of 0 symptoms versus 1 or more versus 2 or more.

Although all clients had at least a one-day opportunity to make an ERVH, some clients were only in the palliative program for as short as a week (n=62); it could be assumed that they may not have had the potential to make an ERVH. Therefore, all of the above analyses were repeated for a sub-population of clients who lived for at least 60 days in order to reliably identify individual determinants associated with ERVH.

Chapter 6

Results

6.1 Sample characteristics

After applying the inclusion criteria previously outlined, the final sample size was 764. The sample size for the sub-population of clients alive for 60 days or longer was 308. Half of the identified clients made one or more ERVH (n=399, 52.2%) as shown in Table 6. Of 399 clients, 377 visited the ED and three quarters of these ED visits resulted in a hospital admission (n=284, 75.3%). Of 399 clients, 22 were directly admitted to hospital with no preceding emergency room visit. Among clients who had a hospital admission (n=306), 60.1% (n=184) died in hospital. The median time from interRAI PC assessment to first ERVH was 24 days (mean=43 days, SD 50.1). Visits to the ED by day of the week were relatively stable with a slight increase on Mondays and Thursdays and a decrease on Saturdays and Sundays. Over a 24-hour period, the number of visits increased from early morning to the afternoon and decreased again in the evening. Of the 308 clients within the sub-population alive for at least 60 days, 67.5% (n=208) had at least one ERVH.

Table 6 *Emergency Department Visits or Acute Hospital Admissions by Palliative Home Care Clients (n=764)*

Characteristics		**% (n)**
Emergency Room Visits or Acute Hospital Admissions		
0		47.8(365)
1+		52.2(399)
ED Visits		
0		50.6(387)
1		30.9(236)
2		11.8(90)
3+ (max of 11)		6.7(51)
	Day of Week Presenting to ED	
	Monday	17.8(67)
	Tuesday	11.6(44)
	Wednesday	13.5(51)
	Thursday	18.0(68)
	Friday	16.7(63)
	Saturday	11.6(44)
	Sunday	10.6(40)
	Time of ED Visit	
	Midnight to 8 am	22.0(83)
	8am to 4 pm	57.8(218)
	4pm to Midnight	20.2(76)
	Died in ED	
	No	94.7(357)
	Yes	5.3(20)
Admissions		
0		59.9(458)
1		29.2(223)
2		8.5(65)
3+ (max of 6)		2.3(18)
	Died During Admission	
	No	39.9(122)
	Yes	60.1(184)

As shown in Table 7, clients who had at least one ERVH had a longer survival time from interRAI PC assessment date to death. Clients with at least one ERVH had a mean survival time of 90.3 days (SD 80.9) with a median survival of 62 days compared to a mean survival time of 54.8 days (SD 67.0) with a median survival of 32 days among clients with no ERVH. Table 7 shows that both clients who had at least one ERVH and clients with no ERVH had similar rates of service use; however, Table 8 shows that clients with at least one ERVH had lower average weekly cost of care for services such as nursing ($273.70 vs. $516.50) and personal support ($84.62 vs. $184.20), as well as a substantially lower overall average weekly cost ($420.60 vs. $789.10).

Table 7 *Service Use by Emergency Department Visits or Acute Hospital Admissions (n=764)*

Characteristics	**No ERVH (n=365) %(n)**	**At Least 1 ERVH (n=399) %(n)**
Survival Days (days from interRAI-PC assessment to death)		
1-30	51.2(187)	26.9(107)
31 - 60	31.5(115)	39.4(157)
61 - 90	11.8(43)	20.1(80)
91- 120	3.0(11)	8.8(35)
121 - 365	2.5(9)	4.8(19)
Interdisciplinary Services		
Nursing		
No	71.4(5)	28.6(2)
Yes	47.6(360)	52.4(396)
Personal Support Services		
No	42.9(117)	57.1(156)
Yes	50.6(248)	49.4(242)
Occupational Therapy		
No	45.5(127)	54.5(152)
Yes	49.2(238)	50.8(246)
Physiotherapy		
No	49.6(280)	50.3(284)
Yes	42.4(84)	57.6(114)
Dietician Services		
No	50.4(329)	49.6(324)
Yes	32.1(35)	67.9(74)
Social Work Services		
No	48.5(340)	51.5(361)
Yes	39.3(24)	60.7(37)
Speech Language Pathology		
No	48.2(356)	51.8(382)
Yes	33.3(8)	66.7(16)

Table 8 *Average Service Use by Emergency Department Visits or Acute Hospital Admissions (n=764)*

Characteristics	**No ERVH (n=365)**	**At Least 1 ERVH (n=399)**
Survival Days (days from interRAI-PC assessment to death)		
Mean (standard deviation)	54.8(67.0)	90.3(80.9)
Median (range)	32.0(1-351)	62.0(1-355)
Average Weekly Cost of Interdisciplinary Services		
Nursing	$516.50	$273.70
Personal Support Services	$184.20	$84.62
Occupational Therapy	$65.98	$36.28
Physiotherapy	$9.84	$12.75
Dietician Services	$6.49	$6.41
Social Work Services	$4.67	$4.92
Speech Language Pathology	$1.46	$1.90
Mean Total Weekly Cost	$789.10	$420.60

Clients with at least one ERVH tended to be slightly younger than those with no ERVH (mean age: 68.8 years vs. 71.2 years), but had a similar proportion of cancer diagnosis (n=359, 90.0% vs. n=313, 85.7%).

In Table 9 each of the hypothesized independent variables in the predisposing, enabling, and need categories were tested at the bivariate level for the entire client sample (n=764).

Table 9 *Descriptive Characteristics of Clients with at least One or More Emergency Department Visits or Acute Hospital Admissions (n=764)*

Variable	Sample %(n)	Proportion With ERVH %(n)	Chi-Sq. Value DF P	Unadjusted Odds Ratio	95% Confidence Interval
PREDISPOSING					
Age					
Aged <75	60.4 (465)	56.5 (263)	8.94	1	
Aged 75+	31.6 (215)	45.5 (136)	1 0.003	0.64	0.48-0.86
Sex					
Male	52.8 (401)	53.9 (216)	0.57	1	
Female	47.2 (358)	50.9 (182)	1 0.45	0.92	0.69-1.22
Marital Status					
Single	48.2 (368)	46.1 (182)	11.91	1	
Married	51.8 (396)	58.7 (216)	1 0.0006	1.65	1.24-2.20
Finds Guidance in Religion or Spirituality					
No/Missing	51.6 (370)	51.9 (186)	1.10	1	
Yes	48.4 (394)	54.1 (213)	1 0.29	1.16	0.88-1.55
Wish to Die at Home					
No/Missing	70.5 (539)	59.7 (322)	41.43 1	1	
Yes	29.4 (225)	34.2 (77)	<0.0001	0.35	0.25-0.48
Wish to Die Now					
No/Missing	95.8(732)	53.3(390)	7.77	1	
Yes	4.2(32)	28.1(9)	1 p 0.05	0.34	0.16-0.75
Advance Directives					
No/Missing	47.8 (365)	66.6 (243)	57.68	1	
Yes	52.2 (399)	39.1 (156)	1 <0.0001	0.32	0.24-0.43
ENABLING					
Provincial/Territorial Health Insurance					
No	0.26 (2)	0 (0)	2.21	1	
Yes	99.7 (753)	52.5 (395)	1 0.14	2.95	0.78-11.19
Caregiver Anger/Distress/Depression & Unable to Continue					

Caring Activities					
No/Missing	84.3 (644)	54.7 (352)	9.73 1 0.002	1	
Yes	15.7 (120)	39.2 (47)		0.53	0.36-0.79
Access to a Physician					
No	1.4 (11)	45.4 (5)	0.20 1 0.65	1	
Yes	98.6 (753)	52.3 (394)		1.32	0.40-4.35
Rural Character					
No	88.2 (674)	52.1 (351)	0.00 1 0.99	1	
Yes	11.8 (90)	52.5 (47)		1.00	0.64-1.55
Client's Cost of Care – Above or Below Median					
Low Cost: less than or equal to $562.90	49.9(360)	59.7(215)	14.8 1 <0.0001	1	
High Cost: greater than $562.90	50.1(361)	45.4(164)		0.59	0.45-0.79
NEED-FOR-CARE: Self-Perceived					
Previous Hospitalization (last 90 days)					
No hospitalization within 90 days	32.5 (248)	58.9 (146)	6.93 1 0.03	1	
31 to 90 days ago	36.4 (278)	50.4 (140)		0.63	0.44-0.90
In the last 30 days	31.1 (238)	47.5 (113)		0.71	0.50-1.0
Believes Physical Function Can Improve					
No/Missing	77.6 (593)	48.6 (256)	21.52 1 <0.0001	1	
Yes	22.4 (171)	67.8 (116)		2.31	1.61-3.31
Self-Rated Depressed Mood					
No	63.9 (465)	53.6 (141)	0.005 1 0.94	1	
Yes	36.1 (263)	53.3 (248)		1.12	0.83-1.51
NEED-FOR-CARE: Evaluated					
Bladder/Bowel Incontinence					
No	71.9 (538)	58.5 (315)	29.00 1 <0.0001	1	
Yes	28.1 (210)	36.4 (76)		0.41	0.29-0.57
Weight Loss (5-10% in 30-180 days)					
No/Missing	49.3 (377)	57.3 (216)	7.67	1	

Yes	50.6 (387)	47.3 (183)	1 0.005	0.67	0.50-0.89
Swallowing Difficulties					
No	71.4 (527)	57.9 (305)	23.04 1 <0.0001	1	
Yes	28.6 (211)	38.1 (80)		0.46	0.33-0.64
Constipation					
No	63.6 (474)	54.4 (258)	1.98 1 0.16	1	
Yes	36.4 (271)	49.1 (133)		0.82	0.61-1.11
Nausea					
No	68.9 (513)	52.6 (270)	0.31 1 0.54	1	
Yes	31.1 (232)	50.2 (116)		0.90	0.66-1.23
Vomiting					
No	80.3 (604)	52.7 (318)	1.12 1 0.29	1	
Yes	19.7 (148)	47.9 (71)		0.81	0.56-1.16
Dizziness					
No	68.1 (505)	54.4 (274)	2.97 1 0.09	1	
Yes	31.9 (237)	47.7 (113)		0.77	0.56-1.04
Potential Delirium					
No	84.2 (624)	57.0 (355)	27.31 1 <0.0001	1	
Yes	15.8 (117)	30.8 (36)		0.35	0.23-0.53
Pressure Ulcer					
No	85.5 (645)	55.2 (348)	6.14 1 0.01	1	
Yes	14.5 (109)	46.7 (45)		0.60	0.40-0.90
Peripheral Edema					
No	67.1 (501)	55.2 (276)	4.83 1 0.03	1	
Yes	32.9 (246)	46.7 (115)		0.72	0.53-0.98
Falls in the last 90 days					
No	74.4 (549)	54.6 (299)	2.78 1 0.10	1	
Yes	25.6 (189)	47.6 (90)		0.78	0.56-1.09
Dyspnea					
No	30.8 (226)	53.1 (120)	0.03 1 0.85	1	
Yes	69.2 (508)	52.3 (265)		1.02	0.75-1.37
Fatigue					
No	0.7 (5)	60.0 (3)	0.13 1 0.71	1	
Yes	99.3 (730)	51.7 (377)		0.66	0.33-1.34

Pain					
(0) Not Present	25.9 (187)	52.9 (99)	0.003	1	
(1,2,3) Present	74.1 (536)	53.2 (285)	1 0.96	1.14	0.83-1.55
Number of Symptoms					
0,1,2,3,4	32.8 (190)	63.7 (121)	10.2	1	
5+	67.2 (389)	49.6 (193)	1 0.001	0.8	0.61-1.07
Activities of Daily Living Hierarchy Scale					
(0) Independent	48.4 (335)	67.2 (225)	45.97	1	
(1,2,3,4,5,6) Dependent	51.6 (357)	41.3 (147)	1 <0.0001	0.44	0.33-0.59
Instrumental Activities of Daily Living					
(0) Independent	4.0 (30)	66.7 (20)	2.64	1	
(1,2,3,4,5,6,8) Dependent	96.0 (718)	51.2 (370)	1 0.10	0.62	0.34-1.15
Cognitive Skills for Daily Decision Making					
(0) Intact	78.0 (574)	58.2 (334)	32.88	1	
(1,2,3,4,5) Impaired	22.0 (162)	32.7 (53)	1 <0.0001	0.36	0.25-0.52
CHESS Scale					
(0,1,2) Stable Health	34.4 (239)	66.1 (158)	28.42	1	
(3,4,5)Unstable Health	65.6 (455)	44.8 (204)	1 <0.0001	0.47	0.35-0.64
Cancer					
No	12.0 (92)	42.9 (39)	3.21	1	
Yes	88.0 (672)	53.4 (359)	1 0.07	1.49	0.96-2.31
Circulatory Disease					
No	86.8 (663)	51.4 (340)	1.26	1	
Yes	13.2 (101)	57.4 (58)	1 0.26	1.27	0.83-1.94
Respiratory Disease					
No	92.7 (708)	52.2 (369)	0.005	1	
Yes	7.3 (56)	51.8 (29)	1 0.95	0.98	0.57-1.69
Neurological Disorders					
No	97.6 (746)	52.4 (390)	0.04	1	
Yes	2.4 (18)	50.0 (9)	1 0.85	0.91	0.36-2.32
Digestive Disorders					
No	96.5 (737)	52.6 (387)	1.48	1	
Yes	3.5 (27)	40.7 (11)	1	0.62	0.28-1.35

			0.22		
Diabetes					
No	92.8 (709)	51.5 (365)	1.43	1	
Yes	7.2 (55)	60.0 (33)	1 0.23	1.41	0.80-2.46
Prior Pneumonia					
No	93.2 (712)	92.7 (370)	0.28	1	
Yes	6.8 (52)	7.3 (29)	1 0.60	1.16	0.66-2.05
Prior Urinary Tract Infection					
No	95.5 (730)	94.74 (378)	1.30	1	
Yes	4.4 (34)	5.26 (21)	1 0.26	1.50	0.74-3.05
Count of Co-Morbidities					
0	54.8 (419)	48.2 (202)	6.7	1	
1,2	41.1 (314)	56.4 (177)	2	1.4	1.0-1.9
3,4,5	4.1 (31)	64.5 (20)	0.03	1.9	0.9-4.2

Note: Odds ratio = 1 indicates reference group

In Table 10 each of the hypothesized independent variables in the predisposing, enabling, and need categories were tested at the bivariate level for the sub-population of clients who were alive for at least 60 days or longer (n=308).

Table 10 *Descriptive Characteristics of Sub-Population Alive for 60 Days or Longer with at least One or More Emergency Department Visits or Acute Hospital Admissions (n=308)*

Variable	Sample %(n)	Proportion With ERVH %(n)	Chi-Sq. Value DF P	Unadjusted Odds Ratio	95% Confidence Interval
PREDISPOSING					
Age					
Aged <75	65.9 (203)	68.5 (139)	0.24	1	
Aged 75+	34.1 (105)	65.7 (69)	1 0.62	0.88	0.53-1.46
Sex					
Male	48.0 (146)	69.9 (102)	0.27	1	
Female	52.0 (158)	67.1 (106)	1 0.60	0.96	0.60-1.55
Marital Status					
Single	47.4 (146)	63.0 (92)	2.58	1	
Married	52.6 (162)	71.6 (116)	1 0.11	1.48	0.92-2.39
Finds Guidance in Religion or Spirituality					
No/Missing	44.2 (136)	67.6 (92)	0.02	1	
Yes	55.8 (172)	67.4 (116)	1 0.97	0.99	0.61-1.60
Wish to Die at Home					
No/Missing	79.5 (245)	71.0 (174)	5.64	1	
Yes	20.4 (63)	54.0 (34)	1 0.01	0.48	0.27-0.84
Wish to Die Now					
No/Missing	97.4(300)	68.0(204)	1.15	1	
Yes	2.6(8)	50.0(4)	1 0.28	0.47	0.11-1.92
Advance Directives					
No/Missing	60.4 (186)	75.8 (141)	14.66	1	
Yes	39.6 (122)	54.9 (67)	1 <0.0001	0.39	0.24-0.63
ENABLING					
Provincial/Territorial Health Insurance					
No	0.3 (1)	0 (0)	2.09	1	
Yes	99.7 (304)	67.8 (206)	1 0.15	2.10	0.29-15.14
Caregiver Anger/Distress/Depression					

& Unable to Continue Caring Activities					
No/Missing	86.7 (267)	68.5 (183)	0.92 1 0.33	1	
Yes	13.3 (41)	61.0 (25)		0.72	0.36-1.41
Access to a Physician					
No	1.6 (5)	60.0 (3)	0.13 1 0.72	1	
Yes	98.4 (303)	67.7 (205)		1.39	0.23-8.48
Rural Character					
No	88.0 (271)	67.2 (182)	0.14 1 0.70	1	
Yes	12.0 (37)	70.3 (26)		1.15	0.55-2.44
Client's Cost of Care – Above or Below Median					
Low Cost: less than or equal to $596.00	49.8(151)	72.8(110)	4.17 1 0.04	1	
High Cost: greater than $596.00	50.2(152)	61.8(94)		0.60	0.37-0.97
NEED-FOR-CARE: Self-Perceived					
Previous Hospitalization (last 90 days)					
No hospitalization within 90 days	36.4 (112)	68.7 (77)	0.70 2 0.70	1	
31 to 90 days ago	31.8 (98)	64.3 (63)		1.03	0.57-1.85
In the last 30 days	31.8 (98)	69.4 (68)		0.82	0.46-1.45
Believes Physical Function Can Improve					
No/Missing	66.9 (206)	64.1 (132)	2.39 1 0.06	1	
Yes	33.1 (102)	74.5 (76)		1.48	0.86-2.55
Self-Rated Depressed Mood					
No	65.3 (194)	67.5 (131)	0.06 1 0.80	1	
Yes	34.7 (103)	68.9 (71)		1.08	0.65-1.79
NEED-FOR-CARE: Evaluated					
Bladder/Bowel Incontinence					
No	84.6 (258)	68.2 (176)	0.76 1 0.38	1	
Yes	15.4 (47)	61.7 (29)		0.75	0.39-1.43
Weight Loss (5-10% in 30-180 days)					

No/Missing	52.9 (163)	79.3 (113)	0.51 1 0.48	1	
Yes	47.1 (145)	65.5 (95)		0.84	0.52-1.35
Swallowing Difficulties					
No	80.6 (245)	69.8 (171)	3.20 1 0.07	1	
Yes	19.4 (59)	57.6 (34)		0.59	0.33-1.05
Constipation					
No	66.1 (201)	69.1 (139)	0.80 1 0.37	1	
Yes	33.9 (103)	64.1 (66)		0.79	0.48-1.30
Nausea					
No	71.8 (217)	67.7 (147)	0.01 1 0.93	1	
Yes	28.1 (85)	68.2 (58)		1.04	0.61-1.79
Vomiting					
No	82.6 (252)	68.2 (172)	0.10 1 0.75	1	
Yes	17.4 (53)	66.0 (35)		0.92	0.49-1.72
Dizziness					
No	68.0 (206)	69.4 (143)	1.28 1 0.26	1	
Yes	32.0 (97)	62.9 (61)		0.74	0.44-1.22
Potential Delirium					
No	91.7 (277)	68.6 (190)	1.66 1 0.20	1	
Yes	8.3 (25)	56.0 (14)		0.58	0.25-1.34
Pressure Ulcer					
No	90.5 (277)	68.9 (191)	3.54 1 0.06	1	
Yes	9.5 (29)	51.7 (14)		0.48	0.22-1.03
Peripheral Edema					
No	75.2 (224)	70.1 (157)	1.94 1 0.16	1	
Yes	25.8 (78)	61.5 (48)		0.70	0.41-1.20
Falls in the last 90 days					
No	75.2 (224)	67.9 (152)	0.15 1 0.70	1	
Yes	24.8 (74)	70.3 (52)		1.18	0.67-2.08
Dyspnea					
No	35.7 (106)	65.1 (69)	0.50 1 0.48	1	
Yes	64.3 (191)	69.1 (132)		1.21	0.74-1.97
Fatigue					
No	1.0 (3)	100.0 (3)	1.48 1	1	
Yes	99.0 (293)	66.9 (196)		0.50	0.14-1.83

			0.22		
Pain					
(0) Not Present	27.6 (81)	69.1 (56)	0.04	1	
(1,2,3) Present	72.3 (212)	67.9 (144)	1 0.84	1.06	0.63-1.77
Number of Symptoms					
0,1,2,3,4	41.3 (102)	74.5 (76)	3.0	1	
5+	58.7 (145)	64.1 (93)	1 0.08	0.75	0.46-1.20
Activities of Daily Living Hierarchy Scale					
(0) Independent	67.2 (191)	74.3 (142)	6.80	1	
(1,2,3,4,5,6) Dependent	32.7 (93)	59.1 (55)	1 0.009	0.59	0.35-0.97
Instrumental Activities of Daily Living					
(0) Independent	5.9 (18)	66.7 (12)	0.12	1	
(1,2,3,4,5,6,8) Dependent	94.1 (285)	67.0 (191)	1 0.97	0.72	0.27-1.88
Cognitive Skills for Daily Decision Making					
(0) Intact	88.6 (263)	68.4 (180)	0.61	1	
(1,2,3,4,5) Impaired	11.4 (34)	61.8 (21)	1 0.43	0.75	0.36-1.57
CHESS Scale					
(0,1,2) Stable Health	44.8 (124)	79.8 (99)	13.18	1	
(3,4,5)Unstable Health	55.2 (153)	59.5 (91)	1 0.0003	0.48	0.29-0.78
Cancer					
No	8.4 (26)	69.2 (18)	0.04	1	
Yes	91.6 (282)	67.4 (190)	1 0.85	0.92	0.38-2.19
Circulatory Disease					
No	87.0 (268)	66.4 (178)	1.17	1	
Yes	13.0 (40)	75.0 (30)	1 0.28	1.52	0.71-3.24
Respiratory Disease					
No	93.2 (287)	67.9 (195)	0.32	1	
Yes	6.8 (21)	61.9 (13)	1 0.57	0.77	0.31-1.91
Neurological Disorders					
No	98.4 (303)	67.3 (204)	0.36	1	
Yes	1.6 (5)	80.0 (4)	1 0.55	1.94	0.21-17.60
Digestive Disorders					
No	97.7 (301)	67.8 (204)	0.35	1	

Yes	2.3 (7)	57.1 (4)	1 0.55	0.63	0.14-2.89
Diabetes					
No	91.2 (281)	68.3 (192)	0.92	1	
Yes	8.8 (27)	59.3 (16)	1 0.33	0.67	0.30-1.51
Prior Pneumonia					
No	95.1 (293)	95.7 (199)	0.41	1	
Yes	4.9 (15)	4.3 (9)	1 0.52	0.71	0.24-2.05
Prior Urinary Tract Infection					
No	96.4 (297)	97.1 (202)	0.88	1	
Yes	3.6 (11)	2.9 (6)	1 0.35	0.56	0.17-1.89
Count of Co-Morbidities					
0	54.2 (167)	64.1 (107)	2.1	1	
1,2	41.9 (129)	71.3 (92)	2	1.39	0.85-2.29
3,4,5	3.9 (12)	75.0 (9)	0.36	1.68	0.43-6.45

Note: Odds ratio 1 indicates reference group

6.1.1 Predisposing Variables

As shown in Table 9, of the predisposing variables, five were statistically significant at the 0.05 level with two exceptions: sex and finding guidance in religion. Of the five significant relationships, four had unadjusted odds ratios of less than 1, indicating that clients with these profiles have decreased odds of having ERVH. They were: clients aged 75 years or older, wished to die at home, wished to die now, and had advance directives present. Only clients who were married had an odds ratio higher than 1, indicating that they had increased odds of having ERVH.

As shown in Table 10, among the sub-population of those who survived at least 60 days, only two variables were significant at the 0.05 level, both of which had unadjusted odds ratios of less than 1 indicating that clients who wished to die at home and had advance directives present had decreased odds of having ERVH.

6.1.2 Enabling Variables

Of the enabling variables, two variables were statistically significant at the 0.05 level with three exceptions: health insurance coverage, access to a physician, and rural character. Clients who had caregivers experiencing distress or had high cost of care (above the median ($562.90)) had decreased odds of ERVH.

Among the sub-population of those who survived at least 60 days, clients who had high cost of care (above the median ($596.00)) had decreased odds of ERVH compared to clients whose costs were less than the median.

6.1.3 Need-for-Care Variables

Of the 30 hypothesized need variables, 11 were significant at the 0.05 level. Of the 11 significant relationships, 10 had unadjusted odds ratios of less than 1, indicating that clients with these characteristics had decreased odds of ERVH: hospitalization in the last 90 days, bladder or bowel incontinence, weight loss of 5% in the last 30 days or 10% in the last 180 days, swallowing difficulties, potential delirium, peripheral edema, pressure ulcer, cognitive skills for daily decision making, ADLH 1+, and CHESS 3+. Clients who believed their physical function could improve had an unadjusted odds ratio greater than 1, indicating increased odds of having ERVH.

Among the sub-population of those who survived at least 60 days only two factors were significant at the bivariate level. Clients with ADLH 1+ and CHESS 3+ had decreased odds of having ERVH.

6.2 Logistic Regression Models

Candidate independent variables were entered into logistic regression models that predicted ERVH. The independent variables that were considered were found to be significant at the 0.05 level in the bivariate testing and included, **predisposing characteristics:** age, marital status, wish to die at home, wish to die now, and any advance directives present; **enabling factors:** caregiver distress, and client's cost of care; and **need variables:** hospitalization in the last 90 days, bladder or bowel incontinence, weight loss of 5% in the last 30 days or 10% in the last 180 days, swallowing difficulties, cognitive skills for daily decision making including delirium, peripheral edema, pressure ulcer, ADLH, CHESS, and belief that physical function can improve. The cognitive skills for daily decision making and delirium items were combined into one variable since presence of delirium has been associated with higher levels of cognitive

impairment and vice versa [49]. The following variables were also tested again in the multivariate model although they were not significant at the bivariate level: sex, dizziness, falls, pain, dyspnea, prior pneumonia, and prior urinary tract infection. Interactions were tested but none were significant at the 0.05 level, so they were not included in the model.

Table 11 shows the logistic regression models. Of the independent variables entered into the model for predisposing only, all variables were significant and independently predicted ERVH except for age and sex. When wish to die at home and wish to die now were entered into the same model they both became insignificant. Therefore, two separate models were created. Both caregiver distress and client's cost of care entered for enabling only were significant predictors of ERVH. Of the variables entered for need only, the majority of variables remained significant except for pressure ulcer, weight loss, falls, pain, and dyspnea. Although prior pneumonia and peripheral edema were only significant at the 0.07 level, they were kept in the model because their inclusion or exclusion did not affect significance of any other variables. When variables from predisposing only, enabling only, and need only were combined all variables remained significant except for wish to die now, peripheral edema, and prior pneumonia. Although believes physical function can improve was significant at the 0.07 level, it was kept in the model because its inclusion or exclusion did not affect significance of other variables. When ADLH and CHESS were tested within the same model they both became insignificant. Therefore, they were entered into two separate models.

Table 11 *Logistic Regression Model for Emergency Department Visits or Acute Hospital Admissions (n=764)*

Independent Variable	Predisposing Only				Enabling Only		Need Only		All			
	Model 1		Model 2						Model 1		Model 2	
	P.E. (S.E.)	Odds Ratio (95% CI)	P.E. (S.E.)	Odds Ratio (95% CI)	P.E. (S.E.)	Odds Ratio (95% CI)	P.E. (S.E.)	Odds Ratio (95% CI)	P.E. (S.E.)	Odds Ratio (95% CI)	P.E. (S.E.)	Odds Ratio (95% CI)
PREDISPOSING												
Married	0.47 (0.15)	1.61 (1.19-2.18)	0.46 (0.13)	1.58 (1.17-2.13)					0.55 (0.17)	1.74 (1.25-2.41)	0.55 (0.17)	1.74 (1.25-2.41)
Wish to Die at Home	-0.84 (0.17)	0.43 (0.31-0.61)							-0.61 (0.19)	0.54 (0.37-0.79)	-0.61 (0.19)	0.54 (0.37-0.79)
Wish to Die Now			-0.82 (0.41)	0.44 (0.19-0.99)								
Any Advance Directives Present	-0.96 (0.15)	0.38 (0.28-0.52)	-1.09 (0.15)	0.33 (0.25-0.45)					-0.94 (0.17)	0.39 (0.27-0.55)	-0.93 (0.17)	0.39 (0.28-0.55)
ENABLING												
Caregiver Distressed					-0.59 (0.20)	0.55 (0.37-0.82)			-0.69 (0.23)	0.50 (0.32-0.79)	-0.67 (0.23)	0.53 (0.38-0.74)
Client's Cost of Care > Median					-0.50 (0.15)	0.61 (0.45-0.81)			-0.60 (0.17)	0.55 (0.39-0.76)	-0.64 (0.17)	0.55 (0.39-0.76)
NEED												
Hospitalization in Last 90 Days							-0.43 (0.21)	0.65 (0.46-0.91)	-0.55 (0.18)	0.57 (0.40-0.82)	-0.51 (0.18)	0.60 (0.41-0.86)
Believes Physical Function Can Improve							0.55 (0.20)	1.73 (1.18-2.55)	0.37 (0.21)	1.45 (0.96-2.10)	0.38 (0.21)	1.46 (0.97-2.21)
Bladder/Bowel Incontinence							-0.63 (0.19)	0.53 (0.37-0.77)	-0.39 (0.20)	0.68 (0.46-1.01)	-0.46 (0.20)	0.63 (0.43-0.94)
Swallowing Problems							-0.58 (0.18)	0.56 (0.39-0.80)	-0.50 (0.18)	0.61 (0.41-0.89)	-0.52 (0.19)	0.59 (0.40-0.86)
Dizziness							-0.33 (0.17)	0.72 (0.51-1.00)	-0.45 (0.18)	0.64 (0.45-0.91)	-0.41 (0.18)	0.66 (0.46-0.94)

Peripheral Edema				-0.31 (0.17)	0.74 (0.51-1.03)				
Any Impairment in Decision Making (incl delirium)				-0.63 (0.19)	0.53 (0.37-0.77)	-0.63 (0.20)	0.53 (0.36-0.79)	-0.65 (0.20)	0.52 (0.35-0.77)
Prior Pneumonia				0.57 (0.32)	1.77 (0.94-3.33)				
Prior Urinary Tract Infection				0.98 (0.41)	2.66 (1.19-5.96)	0.96 (0.42)	2.62 (1.16-3.96)	0.89 (0.31)	2.45 (1.06-5.62)
ADLH 1+				-0.44 (0.17)	0.66 (0.47-0.92)	-0.34 (0.18)	0.71 (0.50-1.01)		
CHESS 3+				-0.39 (0.17)	0.65 (0.47-0.91)			-0.36 (0.17)	0.70 (0.50-0.99)
C-Statistic	0.69	0.67	0.58	0.71		0.77		0.77	

*P.E. = parameter estimate, S.E. = standard error, CI = confidence interval

Among the sub-population that was alive for at least 60 days, the following independent variables were considered based on significance at the 0.06 level in the bivariate testing, **predisposing characteristics:** wish to die at home, and advance directives present; **enabling factors:** client's cost of care; and **need variables:** believes physical function can improve, pressure ulcer, ADLH, and CHESS. Based on clinical feedback, the following variables were also tested although they were not significant the bivariate level: sex, dizziness, falls, pain, dyspnea, prior pneumonia, and prior urinary tract infection. Interactions were tested but none were significant at the 0.05 level so they were not included in the model.

Table 12 shows the logistic regression models for the sub-population. Of the variables entered for predisposing only, both wish to die at home and advance directives present were significant and independently predicted ERVH. In addition, the single variable entered for enabling only, client's cost of care, also remained significant. Of the variables entered for need only, pressure ulcer and CHESS 3+ or more remained significant predictors of ERVH, but believes physical function can improve, ADLH, falls, pain, dyspnea, prior pneumonia, and prior urinary tract infection did not. When predisposing only, enabling only, and need only variables were combined only advanced care directives and CHESS 3+ were significant.

Table 12 *Logistic Regression Model for Emergency Department Visits or Acute Hospital Admissions, Sub-Population Alive for 60 Days or Longer (n=308)*

Independent Variable	Predisposing Only		Enabling Only		Need Only		All	
	P.E (S.E)	**Odds Ratio (95% CI)**	**P.E (S.E)**	**Odds Ratio (95% CI)**	**P.E (S.E)**	**Odds Ratio (95% CI)**	**P.E (S.E)**	**Odds Ratio (95% CI)**
PREDISPOSING								
Wish to Die at Home	-0.60 (0.30)	0.55 (0.30-0.98)						
Any Advance Directives Present	-0.88 (0.25)	0.41 (0.25-0.68)					-0.92 (0.25)	0.40 (0.24-0.66)
ENABLING								
Client's Cost of Care > Median			-0.52 (0.24)	0.60 (0.37-0.97)				
NEED								
Ulcer					-0.81 (0.40)	0.45 (0.20-0.98)		
CHESS 3+					-0.77 (0.25)	0.46 (0.28-0.76)	-0.71 (0.25)	0.49 (0.30-0.81)
C-Statistic	0.64		0.56		0.61		0.66	

*P.E. = parameter estimate, S.E. = standard error, CI = confidence interval

6.2.1 Determinants of Emergency Room Visits or Acute Hospital Admissions

Of the variables in the final logistic regression models, for the entire sample, combining the predisposing, enabling, and need variables, parameter estimates and adjusted odds ratios did not differ considerably between Model 1 containing ADLH 1+ and Model 2 containing CHESS 3+. Goodness of fit calculations indicated a good predictive power of the final model. The c-statistic was 0.77 for both models, where 0.5 indicates chance prediction and 1 indicates perfect prediction (see Table 11).

Married clients had increased odds of ERVH as compared to single clients (OR=1.74). Clients who wished to die at home had decreased odds (OR=0.54). Odds of ERVH were also decreased for clients who had any advanced directives present (OR=0.39).

Clients whose caregivers were distressed (Model 1 OR=0.50, Model 2 OR=0.53) and clients who had cost of care higher than the median ($562.90) had decreased odds of ERVH (OR=0.55).

Clients who had experienced a hospitalization in the last 90 days had decreased odds of ERVH (Model 1 OR=0.57, Model 2 OR=0.60), while clients who believed their physical function could improve had increased odds of ERVH (Model 1 OR=1.45, Model 2 OR=1.46) Clients with bladder or bowel incontinence (Model 1 OR=0.68, Model 2 OR=0.63), swallowing difficulties (Model 1 OR=0.61, Model 2 OR=0.59), dizziness (Model 1 OR=0.64, Model 2 OR=0.66), and difficulty with daily decision making including delirium (Model 1 OR=0.53, Model 2 OR=0.52) had reduced odds of ERVH. Increasing ADLH scores of 1 or more which indicate increasing dependence (OR=0.71), and increased CHESS scores of 3 or higher indicating unstable health (OR=0.70), were also associated with reduced odds. Prior urinary tract

infections were associated with two times increased odds of ERVH (OR=2.45) compared to clients without such infections.

Although very few variables were predictive of ERVH among the sub-population that was alive for at least 60 days, similar parameter estimates and odds ratios were examined. The c-statistic for the final model was 0.66 (see Table 12). Odds of ERVH were decreased for clients who had any advanced directives present (OR=0.40) and CHESS scores of 3 or higher (OR=0.49).

6.2.2 Stratified Models - Determinants of Emergency Room Visits or Acute Hospital Admissions

Table 13 shows the final model stratified based on median time to death. The stratified models showed many of the same variables as the full model. Differences between the full and stratified models were found in the group where clients lived for 46 days or less, where believes physical function can improve, ADLH 1+, and CHESS 3+ were no longer significant but prior pneumonia was. In the group where clients lived for more than 46 days fewer variables stayed in the model, so that only any advanced directives present, and CHESS 3+ remained significant.

Table 13 *Final Logistic Regression Model for Emergency Department Visits or Acute Hospital Admissions, Entire Sample Stratified by Time to Death*

Independent Variables in Final Model (See Table 11)	**Lived for 46 Days or Less (n=390)**		**Lived for More than 46 Days (n=374)**	
	P.E (S.E)	**Odds Ratio (95% CI)**	**P.E (S.E)**	**Odds Ratio (95% CI)**
PREDISPOSING				
Married	1.05 (0.26)	2.87 (1.71-4.81)		
Any Advance Directives Present	-1.08 (0.27)	0.34 (0.20-0.58)	-0.87 (0.23)	0.42 (0.27-0.65)
Wish to Die at Home	-0.78 (0.28)	0.46 (0.26-0.79)		
ENABLING				
Caregiver Distressed	-1.09 (0.37)	0.34 (0.16-0.69)		
Client's Cost of Care > Median	-1.29 (0.27)	0.27 (0.16-0.47)		
NEED				
Hospitalization in Last 90 Days	-1.11 (0.29)	0.33 (0.18-0.58)		
Bladder/Bowel Incontinence	-0.52 (0.28)	0.59 (0.34-1.03)		
Swallowing Problems	-0.60 (0.28)	0.55 (0.32-0.95)		
Dizziness				
Any Impairment in Decision Making (incl delirium)	-0.96 (0.29)	0.38 (0.21-0.68)		
Prior Pneumonia	0.93 (0.45)	2.52 (1.03-6.16)		
Prior Urinary Tract Infection	1.71 (0.60)	5.52 (2.09-15.07)		
ADL Hierarchy 1+				
CHESS 3+			-0.69 (0.23)	0.50 (0.32-0.78)
C-Statistic	0.82		0.65	

P.E. = parameter estimate, S.E. = standard error, CI = confidence interval

Table 14 shows the final model stratified based on need level. The stratified models also showed many of the same variables as the full model, with no new significant variables. Among the group with 0 symptoms versus 1 or more, many fewer variables stayed in the model with only hospitalization in the last 90 days remaining significant. It is important to note that the direction of the association for previous hospitalization is reversed among clients with 0 symptoms, so that clients with 0 symptoms had 4 times *increased* odds of ERVH if they were hospitalized in the last 90 days while clients with 1 or more and 2 or more symptoms had reduced odds. Among the group where clients had 1 or more symptoms, all variables remained significant except for prior urinary tract infection, while among the group where clients had 2 or more symptoms all variables remained significant.

Table 14 *Final Logistic Regression Model for Emergency Department Visits or Acute Hospital Admissions, Entire Sample Stratified by Need Level*

Independent Variables in Final Model (See Table 11)	**0 Symptoms (n=44)**		**1 or More Symptoms (n=720)**		**2 or More Symptoms (n=537)**	
	P.E (S.E)	**Odds Ratio (95% CI)**	**P.E (S.E)**	**Odds Ratio (95% CI)**	**P.E (S.E)**	**Odds Ratio (95% CI)**
PREDISPOSING						
Married			0.59 (0.17)	1.81 (1.31-2.51)	0.55 (0.19)	1.74 (1.20-2.53)
Any Advanced Directives Present			-1.08 (0.17)	0.34 (0.24-0.48)	-0.79 (0.19)	0.45 (0.31-0.66)
Wish to Die at Home			-0.79 (0.18)	0.45 (0.32-0.65)	-0.77 (0.21)	0.46 (0.31-0.69)
ENABLING						
Caregiver Distressed			-0.86 (0.23)	0.42 (0.27-0.66)	-0.87 (0.25)	0.42 (0.25-0.69)
Client's Cost of Care > Median			-0.60 (0.17)	0.55 (0.40-0.76)	-0.57 (0.19)	0.57 (0.39-0.82)
NEED						
Hospitalization in Last 90 Days	1.41 (0.71)	4.09 (1.02-16.40)	-0.65 (0.18)	0.52 (0.40-0.76)	-0.56 (0.20)	0.57 (0.38-0.85)
Prior Urinary Tract Infection					0.74 (0.38)	2.11 (0.99-4.47)
C-Statistic	0.67		0.72		0.72	

*P.E. = parameter estimate, S.E. = standard error, CI = confidence interval

The full model among the sub-population that was alive for at least 60 days was stratified and tested by median time to death (119 days) as well as need; however, no substantial differences were found.

6.3 Survival Analysis

The Kaplan-Meier method was used to examine time to ERVH following interRAI PC assessment (Figure 6). The horizontal axis represents the time in days, with an observation period of up to 365 days. Individuals were right-censored at time of the event (i.e. ERVH), if no events occurred then clients were censored at death (all deaths occurred up to 365 days after interRAI PC assessment). The vertical axis represents the cumulative proportion of clients still at risk of ERVH. There were 399 events to observe in the survival analysis. The pattern of the survival curve suggests that approximately two thirds (65%) of clients had an ERVH within the first 100 days since interRAI PC assessment, with the number of events gradually decreasing thereafter.

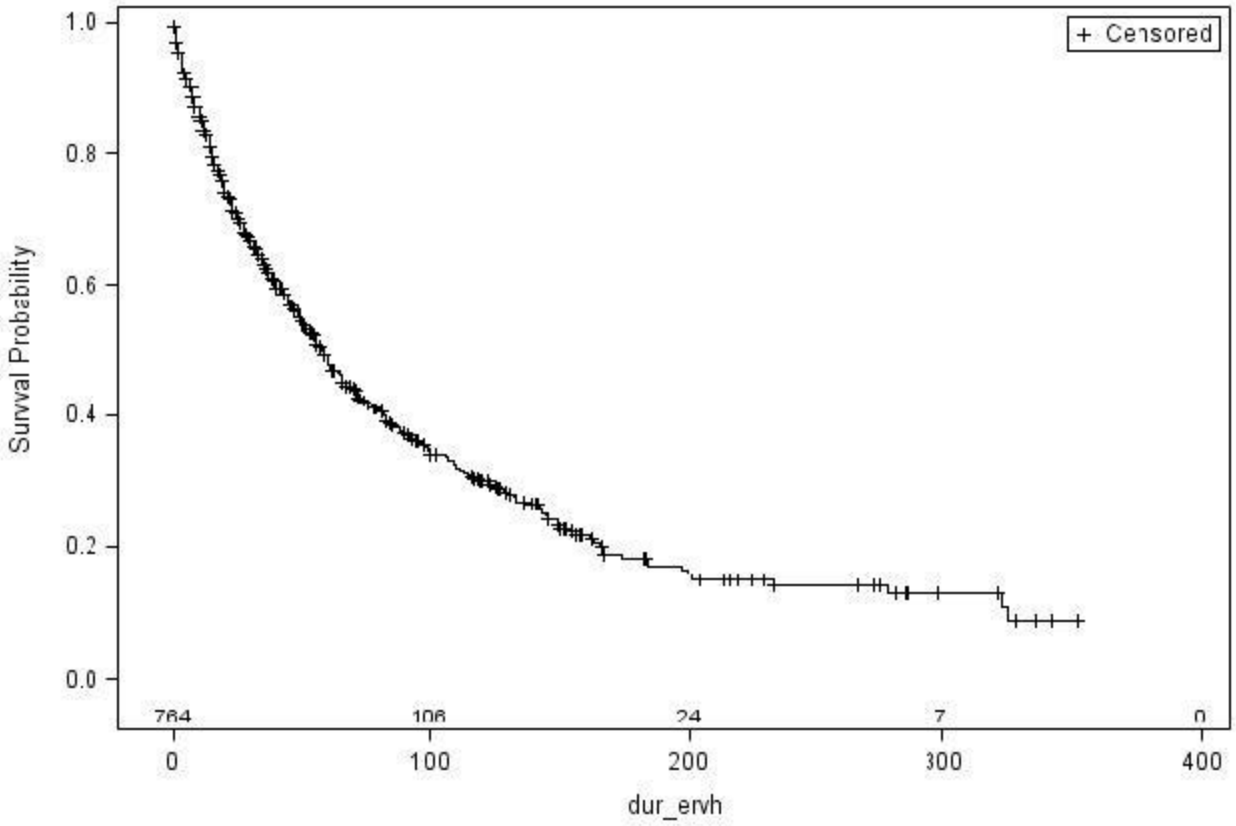

Figure 6. Plot of the survival curve for the emergency department visits or acute hospital admissions (n=764).

6.3.1 Cox Regression Models

Although 3 dependent variables were tested (i.e., ED visits, hospital admission, and ERVH) findings were very similar. Therefore, only models for ERVH were considered. Clients who did not experience an ERVH within 1 year of the interRAI PC assessment were censored at time of death. The independent variables that were entered into the Cox proportional hazard model were found to be significant at the 0.25 level in the log-rank test of the Kaplan Meier. The independent variables included **predisposing characteristics:** age, sex, wish to die at home, and any advanced directives present; **enabling factors:** caregiver distress, access to physician, and client's cost of care; and **need variables:** bladder or bowel incontinence, weight loss, swallowing difficulties, dizziness, cognitive skills for daily decision making including delirium, pain, fatigue, dyspnea, CHESS, congestive heart failure, chronic obstructive pulmonary disease, prior pneumonia, and prior urinary tract infection. Interactions between independent variables and interaction with time were tested, but none were significant at the 0.05 level, so they were not included in the model.

Table 15 shows the Cox proportional hazards models. Of the independent variables entered into the model for predisposing only, all variables were significant and independently predicted ERVH except for age. Of the variables entered for enabling only, client's cost of care remained significant. Of the variables entered for need only, swallowing difficulties, dizziness, prior pneumonia, and prior urinary tract infection remained significant and independent predictors of ERVH. In the final model combining all 3 categories, all variables remained significant and independent predictors of ERVH except for female sex, prior pneumonia, and swallowing difficulties. The final model was stratified and tested by need level; however, no substantial differences were found.

Table 15 *Cox Regression Model for Emergency Department Visits or Acute Hospital Admissions (n=764)*

Independent Variable	Predisposing Only		Enabling Only		Need Only		All	
	P.E (S.E)	**Hazard Rate (95% CI)**	**P.E (S.E)**	**Hazard Rate (95% CI)**	**P.E (S.E)**	**Hazard Rate (95% CI)**	**P.E (S.E)**	**Hazard Rate (95% CI)**
PREDISPOSING								
Female	-0.22 (0.10)	0.80 (0.6-0.97)						
Wish to Die at Home	-0.36 (0.13)	0.69 (0.54-0.90)					-0.36 (0.14)	0.70 (0.53-0.91)
Any Advance Directives Present	-0.27 (0.11)	0.78 (0.62-0.94)					-0.30 (0.11)	0.74 (0.60-0.92)
ENABLING								
Client's Cost of Care > Median			-0.54 (0.10)	0.58 (0.47-0.71)			-0.55 (0.11)	0.57 (0.46-0.71)
NEED								
Swallowing Difficulties					-0.27 (0.13)	0.76 (0.59-0.99)		
Dizziness					-0.24 (0.11)	0.79 (0.63-0.98)	-0.27 (0.11)	0.76 (0.61-0.96)
Prior Pneumonia					0.38 (0.19)	1.46 (0.98- 2.16)		
Prior Urinary Tract Infection					0.48 (0.23)	1.63 (1.03-2.57)	0.71 (0.24)	2.04 (1.28-3.24)

*P.E. = parameter estimate, S.E. = standard error, CI = confidence interval

Among the sub-population that was alive for at least 60 days the following independent variables were considered, **predisposing characteristics:** age, wish to die at home, and any advanced directives present; **enabling factors:** access to physician, and client's cost of care; and **need variables:** belief that physical function can improve, swallowing difficulties, pressure ulcer, ADLH, CHESS, congestive heart failure, and renal failure. Interactions between independent variables and interactions with time were tested but none were significant at the 0.05 level, so they were not included in the model.

Table 16 shows the Cox proportional hazard models for the sub-population alive for at least 60 days or longer. Of the independent variables entered for predisposing only, age was no longer significant. Of the variables entered for enabling only, client's cost of care remained significant. Among the need only variables, pressure ulcer, and CHESS 3+ remained significant and independent predictors of ERVH. When combining all 3 categories, only advance care directives, and CHESS 3+ remained significant. The final models were stratified and tested by need level; however, no substantial differences were found.

Table 16 *Cox Regression Model for Emergency Department Visits or Acute Hospital Admissions, Sub-Population Alive for 60 Days or Longer (n=308)*

Independent Variable	Predisposing Only		Enabling Only		Need Only		All	
	P.E. (S.E.)	Hazard Rate (95% CI)	P.E. (S.E.)	Hazard Rate (95% CI)	P.E. (S.E.)	Hazard Rate (95% CI)	P.E. (S.E.)	Hazard Rate (95% CI)
PREDISPOSING								
Wish to Die at Home	-0.40 (0.19)	0.67 (0.46-0.98)						
Any Advance Directives Present	-0.36 (0.15)	0.70 (0.52-0.94)					-0.30 (0.16)	0.74 (0.54-1.01)
ENABLING								
Client's Cost of Care > Median			-0.25 (0.14)	0.78 (0.59-1.03)				
NEED								
Ulcer					-0.58 (0.29)	0.56 (0.32-0.98)		
CHESS 3+					-0.41 (0.15)	0.65 (0.49-0.88)	-0.35 (0.14)	0.69 (0.53-0.94)

*P.E. = parameter estimate, S.E. = standard error, CI = confidence interval

6.3.2 Effects of Independent Variables on Hazard Rate of ERVH

According to Table 15, the final model combining predisposing, enabling, and need variables indicates that the hazard of ERVH was 2.04 times more likely among those with prior urinary tract infections compared to clients without the infection. Clients who wished to die at home (HR=0.70), had any advanced directives present (HR=0.74), whose cost of care was higher than the median (HR=0.57), and who experienced dizziness (HR=0.76), had reduced hazard rates of ERVH.

Similarly, among the sub-population of clients alive for at least 60 days or longer clients who had any advanced care directives present and CHESS scores of 3 or higher had reduced hazard rates of ERVH (HR=0.74, HR=0.69 respectively).

Chapter 7

Discussion

There are two studies that analyzed predictors of ED visits and acute hospital admissions among palliative home care clients in Canada, but they had important methodological limitations. This study contributes to the literature by being the first to use the Andersen-Newman framework for health service utilization to examine predictors of ERVH among palliative home care clients. The objectives of this study were to determine whether the predisposing, enabling, and need variables were associated with ERVH, and to determine which level of the health service utilization framework best explained and predicted ERVH. Since it was previously determined that HNHB CCAC is comparable to the other 13 CCAC sites, study findings can be extrapolated beyond the study sample to palliative home care clients receiving services from any other CCAC sites in Ontario.

7.1 Descriptive Characteristics of Clients

The sample of palliative home care clients included individuals who received services between April 2008 and July 2010. Half of the identified clients had at least one or more ERVH during the time period from interRAI PC assessment to death. Because there is variability in length of follow up among studies, direct comparisons of ED use in this group of clients with that reported in literature may not always be appropriate. Other researchers have reported rates of ED use of 6.0% [18], 17.0% [24], 26.6% [48], and 35% [49] among palliative clients. The proportion of clients with at least one ERVH is much higher in this study than in other studies due in part to the longer observation of up to one year before death.

Of the clients who had an ED visit, three quarters were admitted and more than half died in the hospital. It may be the case that clients who were in their final moments of life and who were in need of resources that can only be provided in hospital were appearing in the ED for admission. It might be better for such clients to be directly admitted to hospitals; however, it is understood that the quickest route to hospital admission may only be through the ED at the moment.

Some variability was observed with respect to ERVH by the time of day and day of the week. This finding is also supported by Lawson et al. (2008); however, the only difference is that in this study proportions dropped on weekends, perhaps suggesting that ED visits may be connected to calls to physician offices on weekdays and told to visit the ED. Therefore without the physicians' confirmation clients might otherwise wait. Surprisingly, many of the ED visits occurred during daytime hours, when clients had access to physicians and home care services. Again, these visits could be connected to calls to physician offices or perhaps these clients were experiencing symptoms (e.g., shortness of breath) which they thought required "urgent" care, and so they turned to the ED for the fastest access to a medical professional.

Cost of care services differed greatly between clients with an ERVH and clients without, indicating that clients with an ERVH have lower utilization of community-based palliative care services. Clients with at least one ERVH had a longer median survival time from interRAI PC assessment to death (62 days) but lower average weekly cost of care for services. On the other hand, clients with no ERVH were closer to death (median survival time of 32 days) and perhaps more accepting of their existing and newly developing symptoms. Therefore, they received more formal services, specifically increased nursing and personal support services, in order to remain at home. This finding is supported by Seow et al. (2010) who report that more hours of home

care services (including nursing to alleviate pain and dyspnea before these symptoms exacerbate and personal support services to prevent caregiver burnout) were associated with reduced use of acute care [90].

In end of life, the role of social workers involves helping clients and family members to deal with personal and social issues of the client`s impending death, including grief and bereavement support for caregivers [91]. Social workers also have competence in advocating for clients and family members for needed services, including pain management [91]. Surprisingly, very few clients in this study received social work services. Many case managers are social workers suggesting that social work is perhaps inadequate at times of crisis among palliative populations.

7.2 Determinants of Emergency Room Visits or Acute Hospital Admissions

Variables that were significant predictors of ERVH in any of the final models will be discussed in this section.

The only factor that increased the likelihood of ERVH among the predisposing characteristics was marital status. Clients who were married had increased odds of ERVH. This finding is contrary to the work of Lawson et al. (2008), who reported that clients cared for by their parents or relatives were more likely to experience an ED visit compared to clients cared for by a spouse or partner; however, the study also included clients in an outpatient clinic and inpatient palliative care unit which could have affected findings. Although individuals at the end of life have multiple caregivers, more than half are cared for primarily by their spouse [92]. Caregivers may have never cared for someone with a terminal illness, may have no knowledge regarding the required medications and may have no knowledge of the disease progression.

Therefore, they may not know what actions to take in the event of new symptoms arising or a change in health condition. Further, caregivers may be confused as to who to contact during crucial times since clients may be receiving services from a number of health professionals (e.g., family physicians, cardiologists, oncologists). There is currently no policy in place to delineate a most responsible physician (MRP), therefore caregivers and clients may turn to the ED as the fastest route to relieve distress.

At the end of life, the quality of care is highly dependent on eliciting client and family caregiver wishes. Clients who wished to die at home and clients who had any advanced care directives present had reduced odds of ERVH, indicating that services received were usually in accord with their wishes. This finding is supported by Schonwetter et al. (2008) who reported that clients with a do-not-resuscitate order prefer less aggressive treatment and tend to place greater emphasis on quality of life rather than on quantity of life [23].

Although documentation of client wishes is important in providing good quality care, end of life preferences are dynamic as it is difficult for clients to accurately predict their future preferences, emotions, and behaviours. Since a client's emotional context at time of prediction may differ considerably from one experienced at time of the future event, decisions around end of life treatment options may change over time [93, 94, 95].

Among the enabling factors, caregiver feelings of distress were associated with reduced odds of ERVH. One possible explanation could be that caregivers' levels of distress were possibly based on the clients' proximity to death. The median time to death for the entire study sample was only 46 days. Although caregivers were distressed, they might have understood and accepted that their loved ones were approaching death, and therefore wanted to keep them at

home to die in a familiar environment surrounded by their family and friends. This finding indicates that caregivers should receive increased formal services based on the clients' proximity to death.

Clients with high cost of care (above the median) for all interdisciplinary services had reduced odds of ERVH. This finding is supported by Seow et al. (2010) who reported that increased use of formal home care services, which indicate increased overall cost of care among palliative care clients, leads to reductions in acute care service use [90]. When hours of services are increased, service providers are able to anticipate and address client needs at home, thereby avoiding future ED visits.

Clients who experienced a hospital admission in the last 90 days before interRAI PC assessment had decreased odds of ERVH, which is contrary to the work by Brink et al. (2011) reporting that previous hospital admission was a significant determinant of ED use [49]. Reduced odds of ERVH among clients with previous hospital admission could be a function of the client's and caregiver's choice. In addition, many clients who were previously hospitalized were perhaps referred to the Hamilton CCAC after being discharged, thereby resulting in mobilized palliative care services to keep them at home.

Clients who believed that they were capable of improved performance in physical function had increased odds of ERVH. Perhaps these clients had not come to terms with the fact that they were nearing death, and so they were more willing to go to the ED to continue aggressive treatments if they had the slightest hope that their health could perhaps improve. On the other hand, if they believed that their health status would remain stable or continue to

deteriorate, they may have preferred comfort care provided through home care services over life-extending measures.

As clients approach death they enter a phase of progressive health conditions that affect one or more organ systems. Symptoms such as bladder or bowel incontinence, swallowing difficulties, and dizziness have all been associated with reduced odds of ERVH. Clients may experience such symptoms as a direct result of the disease process. Weakness, decreased cognitive function, and overall body malfunction may often leave the mouth dry and impair the ability to swallow [96]. In addition, fatigue and loss of sphincter control can lead to incontinence of the urine or stool, which again is a very common occurrence [96]. Further, clients may sleep for long periods of time, become disoriented, have an altered sense of perception, and decreased fluid intake, which may lead to dizziness [96]. These symptoms are typical among clients near the end of life, they may not require invasive treatment, and they may not be alarming when understood and expected. Therefore, the proximity of these symptoms to expected death may explain their negative association with ERVH use if death at home is the preferred outcome.

Similarly, difficulty with daily decision making including delirium, dependence while performing activities of daily living (ADLH 1+), and health instability (CHESS 3+) were all associated with reduced odds of ERVH. As physical and cognitive functions decline and health conditions becomes more unstable, clients are perhaps closer to death, more accepting of their fate and therefore prefer more comfort care.

The only evaluated need variables which were found to increase the risk of ERVH were prior pneumonia and prior urinary tract infections. Cintron et al. (2003) reported that pneumonia was a significant predictor of hospital admission among clients receiving hospice care [18].

Clients could still be experiencing symptoms even after going to the hospital, if the infections were not properly treated or if the antibiotics prescribed were not effective. Such infections may also be related to the client's general health state. For example immobility, swallowing difficulty, and dehydration are common among end of life clients and increase the risk of pneumonia and urinary tract infections [97, 98]. Therefore, even with proper treatment, infections could still reoccur throughout the client's last few months or weeks of life.

Clients with such infections may have increased odds of ERVH because physicians may decide to offer comfort measures to reduce pain rather than treat the infection [99]. Physicians' choice not to treat an infection may be part of a palliative care plan since a serious infection may produce sedation and coma, resulting in a peaceful death [99]. Even if comfort measures are provided to reduce pain, clients may go to hospital for other symptoms associated with the infections (e.g., shortness of breath, delirium, and fever). In cases where physicians prescribe antibiotics, clients may be required to come into the office for diagnostic tests; however, if physicians are working out of a hospital clients must then go through the ED for the tests. Another possible explanation could be that about 30% of the sample had difficulty swallowing, making oral antibiotics difficult to use. Perhaps intravenous lines, which are only available in a hospital setting, were employed. Prescription of antibiotics may be part of a palliative care plan if the infection produces discomfort; however, this treatment plan may require emergency room visits for diagnostic tests, for intravenous lines if swallowing difficulties are present, and for potential adverse reactions to antibiotics [99].

The most commonly cited reason for ERVH, pain [23, 24, 48], was not a predictor in this study. Since the majority of clients in this study had a diagnosis of advanced cancer and pain is among one of its most distressing symptoms, alleviation of pain would be a primary focus of

home care services for these clients [100]. Another possible explanation could be that clients had access to other resources such as advanced care paramedics. Although pain management is usually performed by hospital personnel, less emphasis is put on pain management by emergency medical services systems, specifically advanced care paramedics. Advanced care paramedics are a level of practitioners who typically carry approximately 20 different medications including morphine and are able to perform pharmacological chemical pain relief for various conditions, including cancer related pain [101].

The final regression model for the entire sample and for the sub-population alive for at least 60 days, had some common significant variables – any advance care directives present and CHESS 3+. This suggests that these two variables are consistent and important predictors of ERVH regardless of short or long survival time.

7.3 Stratified Models - Determinants of Emergency Room Visits or Acute Hospital Admissions

The final model stratified based on median time to death showed many of the same variables as the full model and sub-population model. The lived for 46 days or less model is very similar to the full model, while the lived for more than 46 days is the exact same as the final model for the sub-population who lived for at least 60 days or longer. A potential reason for the similarities is that clients who lived for 46 days or less (n=390) made up half of the cases in the full model (n=764); while clients who lived for 46 days or longer (n=374) made up all of the cases of the full model for the sub population who lived for 60 days or longer (n=308).

The main difference between the final model and the model stratified by need level is found within the 0 symptoms group, where the only significant and independent predictor of ERVH was hospitalization in the last 90 days. While in the final model clients who had previous

hospitalization had reduced odds of ERVH, in the stratified model clients who had no symptoms had four times *increased* odds of ERVH if they had a previous hospitalization. The difference in odds between the two models could be because in the stratified group of 0 symptoms, clients were asymptomatic and so they may have had other "needs" which could not be addressed through the interdisciplinary services. Such clients may not have been coping well with their prognosis, may have had increased anxiety, and may have been experiencing existential distress. If there is adequate control of symptoms or if there are no physical symptoms, psychological and existential factors are other sources of distress which may contribute to ED visits.

Literature has emphasized that perceived and evaluated need is a primary determinant of ERVH among older adults in the general population. When examining the stratified models based on 1 or more and 2 or more symptoms, predisposing and enabling variables remained significant and independent predictors of ERVH when need was adjusted for. In addition, the predisposing only Model 1 provided good discrimination in predicting ERVH with a C-statistic of .69, enabling only had a C-statistic of .58, and need only had a C-statistic of .71. These statistics suggest that the predisposing characteristics are nearly as good as the need variables in predicting ERVH among palliative home care clients.

7.4 Effects of Independent Variables on the Hazard Rate of ERVH

The survival curve shows that majority of events (ERVH or censored at death) occurred within the first 3 months from interRAI PC assessment. When considering that the median survival time for clients with no ERVH was one month (32 days) and for clients with at least one ERVH was two months (62 days), this one month difference may be crucial among a palliative population and would indicate that both client groups are distinct from each other.

Because logistic regression does not utilize information regarding the point in time during which the event occurred, Cox regression was also performed. Both the logistic regression and Cox regression models should yield similar results when the length of follow-up is sufficiently short.

Since length of follow-up from interRAI PC assessment to death varied among the sample, ranging from a few days to one year, the final logistic regression and the final Cox regression models were not identical; however, the models did include some of the same variables such as wish to die at home, any advanced care directives present, client's cost of care, dizziness, and prior urinary tract infection. The final logistic regression model and the final Cox regression model for the sub-population alive for at least 60 days or longer included all of the same variables – any advanced care directives, and CHESS 3+. The length of follow-up among this sub-population did not vary as much which perhaps led to the exact same results.

The above findings suggest that there is a strong agreement between the logistic regression and Cox regression models that the following variables are all independent predictors of ERVH among palliative home care clients – predisposing characteristics: wish to die at home, and any advanced care directives; enabling factors: client's cost of care; and need variables: prior urinary tract infections and CHESS 3+.

7.5 Andersen-Newman Framework

According to McKillip (1987), *needs* are problems of a target group that can be solved [102]. The main approach taken at the end of life involves setting goals of care (i.e., management strategies to relieve suffering) rather than seeking problem-based solutions for issues that may cause suffering [103]. Although symptoms (e.g., shortness of breath, delirium,

and weight loss) are usually treated among older adults in the general population, symptom *control* or *management* rather than treatment for the underlying source of such symptoms may be warranted at the end of life. Therefore, need as a component of the individual determinants may not always be appropriate for a palliative population.

7.6 Limitations

There are limitations in this study that should be noted. Certain items and scales from the interRAI PC assessment which may have been potential predictors of ERVH were excluded from the study due to missing data: awareness of prognosis, hallucinations, fever, dehydration, CPS, and DRS.

In addition, other potential predictors of ERVH cited in the literature could not be assessed as the interRAI PC assessment does not capture them, including: median household income, education, race, and cultural beliefs about end of life directives. Some studies have suggested that lower socioeconomic status (SES) (i.e., education and income) is associated with less utilization of HPC services [23, 47, 104], but because the interRAI PC does not ask about SES this study was unable to examine whether lower SES was also associated with reduced use of ERVH.

Oral thrush, a yeast infection in the mouth, was not captured either in the interRAI PC. The infection can cause pain or difficulty swallowing and is very common among clients with advanced cancer as their immune systems are weak [105]. This study was unable to capture the CCAC case manager caseload, which is defined as the number and characteristics of clients for which the case manager is responsible [106]. If case managers have a very large caseload, they may have greater difficulty in addressing the needs of their clients on a timely basis. Thus their

ability to prevent crises (e.g., emergency department visits) and to support clients to remain in their own home may be affected.

The purpose of advance care planning is to allow clients to express their preferences for future care, with the assumption that their projection of treatment correctly reflects how they would actually feel in that state. However, preference stability may diminish over time because clients' preferences may change, for example, with changes in their health [93]. Therefore, clients' wishes to die at home and any directives present may not accurately represent clients' actual preferences at every point near their end of life.

All clients' costs of care, from day of interRAI PC assessment to death, were included in computing the average weekly cost of care for each service discipline. However, the average costs may be inaccurate since clients who had an ERVH were unable to incur costs for the period of time they were in the hospital but would have perhaps incurred costs otherwise.

Rates of unplanned ED visits may be inflated as they may include visits from clients who have family physicians but were unable to get an appointment with them. In such cases clients may go to the ED simply to seek advice from a physician, rather than for symptom or pain management. In addition, it is unknown whether clients had initially made a call to a family physician who advised them to go to the ED because they were working out of a hospital instead of their clinic for that period.

Further, the main reasons for ERVH were unknown, as access to the NACRS and DAD elements which documented them were not provided. Although access was given to information about the most responsible diagnosis for a client's stay in hospital, this item does not necessarily represent the actual presenting complaint, as "palliative care" can be recorded as the most

responsible diagnosis. Therefore, interRAI PC items found to be significant in this study could not be compared to the actual presenting complaints to assess concordance.

The main weakness of this study is the single observation for the independent variables. Only one interRAI PC assessment was completed for all clients, although survival times ranged from a few days to one year. Clients assessed closer to death are more likely to show symptoms than those further away as the disease processes advance. Although some measurements are probably stable (e.g., comorbid conditions), others will change as time to death grows closer (e.g., physical dependency, symptoms, infections, and advanced care directives). Having repeat interRAI PC assessments would have allowed a more dynamic evaluation of the impact of transitions in health.

7.7 Strengths

The use of the interRAI PC as a comprehensive standardized assessment was a great strength of this study. The items in the assessment capture multiple key domains related to function, health, social support, service use, and discharge information. Further, the assessment is performed by trained health professionals. The interRAI PC gives clinicians an incentive to collect accurate data as it allows for assessment of client needs, determines eligibility for services, and determines the nature, intensity, and duration of services required to ensure that the right services are provided to clients at the right time.

Another strength of this study is the availability of the Local Health Integrated Network Integrated Data Stores (LHIN IDS) which have information on emergency department visits (NACRS database) and hospital admissions (DAD database). At this moment no other CCACs have access to such information on a regular basis. Access to the above databases allowed for a

more complete description of the number, date, and time of ERVH between the period of palliative home care program enrolment and death.

To our knowledge the Andersen-Newman framework for health service utilization has never been used as a basis for studies involving palliative clients. As this study is the first to employ the framework among such a population, it helped to emphasize the importance of the predisposing characteristics in conjunction with the need variables in predicting ERVH among a palliative home care population.

As previously noted, the HNHB CCAC is comparable to other CCACs in terms of percentage of end of life clients receiving services and average expenses. The socioeconomic status of individuals living within the HNHB region is also very comparable to that of Ontario and Canada. In addition, the HNHB CCAC is the largest in Ontario, allowing for a large, representative, and heterogeneous sample; therefore, study findings have increased applicability to other CCACs.

7.8 Implications

Since the interRAI PC was designed to provide a comprehensive assessment of end of life clients, future modifications to the assessment should be considered to help increase its applicability in ERVH research. For example, other potential determinants of ERVH such as median household income, education, race, specification of urban versus rural besides postal code, oral thrush, and assignment of MRP should be included in the assessment. In addition, the interRAI PC assessment would benefit from the inclusion of infections as a separate domain of the disease diagnoses.

The findings of this study may have implications for care planning as they provide a context for understanding determinants of ERVH among a palliative home care population. Although marital status has been identified as a non-modifiable risk factor associated with ERVH, the predictor is of value for informing service planners as it helps identify married clients as being at higher risk for ERVH. Caregivers, primarily spouses, often have little or no experience or information to guide them even though they are key players in providing home care. Therefore, identification of this predictor will allow service providers to adjust their care plans to include discussions with caregivers about what to expect during the client's dying process, including physical symptoms and psychological issues. Increased knowledge may reduce caregivers' anxieties by helping them to anticipate issues and learn what to do under various circumstances, thus reducing unnecessary ERVH. Identification of marital status as a non-modifiable risk factor could be used for risk-adjustment when comparing outcome measures (e.g., ERVH) across CCAC sites.

This study emphasizes the importance of advance care directives and preference for place of death in relation to ERVH. The implications of this study are important not only to service providers but also to clients. The main purpose of advance care directives is to allow clients to express their preferences for care if at any point they are unable to speak for themselves. However, changes in health status as clients' conditions worsen may also lead to changes in treatment preferences and preferred place of death. Discussions around advance care directives and preferred place of death should be conducted as a process through which clients are able to reflect on their preferences after experiencing a change in their health. Hence, more than one interRAI PC assessment should be completed as clients' health statuses change or deteriorate.

Pneumonia and urinary tract infections as modifiable risk factors have implications for education provided to service providers, caregivers, and clients. Improvements are required in the identification of signs and symptoms of infections at the end of life and their documentation in the interRAI PC. Anticipation and early identification will support the development of a care plan to avoid ERVH. Study findings also have implications for care planning. Since aspiration is one of the most important risk factors for pneumonia among individuals at the end of life [97], it is assumed that many of the cases in this study represented aspiration pneumonia. Therefore, in cases where clients with swallowing difficulty may breathe in food or fluids into the lungs causing infection, speech language pathologists help to develop compensatory strategies for swallowing efficiency, and nutritionists provide supportive dietary modifications [107].

The results of this study helped to identify aspects of the Andersen-Newman framework that could be revised to guide research concerning ERVH among palliative home care clients. Although Andersen and colleagues have suggested that different health care types (i.e., hospital, physician, and dentist) require different configurations of explanatory variables, they may not have considered the different population types (e.g., older adults in the general population versus end of life). The framework should consider including knowledge or awareness of prognosis (e.g., I will only be alive for another 6 months) as it is different than knowledge of disease (e.g., I have advanced cancer) and preferred location of death (home or hospital), both of which may influence ERVH at the end of life. Both concepts fit into the beliefs component of the predisposing characteristics. Further, infections should be placed in the evaluated component of the need characteristics, separate from the symptoms and diagnoses variables. Most importantly a revision of the Andersen-Newman framework should include renaming the *need* component to *health status*. Health status has been defined as the range of manifestation of a disease, including

symptoms, functional limitation, and quality of life [107].Quality of life would be the difference between the actual and desired function. Individual health status can consist of a combination of both an objective measure by an observer (e.g., physician) plus the individual's subjective impressions (e.g., pain or discomfort, overall perception of health) [108].

Findings from this study will provide a base for the Integrated Client Care Project – Palliative, a multi-year initiative co-sponsored by the MOHLTC. The project involves developing, implementing, and evaluating CCAC sites to plan the transition to a more integrated client care model, including payment for specific outcomes. One of the goals of the project is to improve health outcomes for palliative clients in the community by changing client utilization of acute services, (i.e. avoidable hospitalizations). The project will be using many of the same coordinated assessment processes used in this study, including the standardized interRAI PC tool, the CCAC CHRIS data system, LHIN IDS, DAD, and NACRS systems for performance and outcome measurement.

7.9 Future Research

After addressing many of the limitations noted above, these analyses could be replicated across different CCACs as they have access to many of the resources used in this study. All CCACs, except for one, have adopted the electronic interRAI PC assessment which is submitted to the Ontario Association of Community Care Access Centres (OACCAC). Researchers from each CCAC can compare utilization of ERVH using CHRIS case hold data to indicate when clients have an ERVH and compare predictors of ERVH using the interRAI PC assessment. All CCACs could then come together to discuss findings, identify branches that are exceptional performers, identify their practices, and promote uptake of these practices.

Research regarding the appropriateness of ED use is required to understand ERVH among palliative home care clients. Factors such as whether the decision to use the ED was preceded by an attempt to contact a family physician, whether contacts were successful, whether physicians worked in a hospital or a clinic, and whether clients wished to die in a hospital setting (e.g., palliative care unit) may determine whether or not clients present to the ED.

Future research should address the reasons clients go to the ED when experiencing pneumonia and urinary tract infection. Are symptoms experienced during times when services are not available (e.g., nights), are physicians withholding antibiotics, or are clients experiencing adverse reactions to antibiotics? Further, research is needed to explore whether or not antibiotic treatment is beneficial, particularly with respect to longevity and improving symptoms at the end of life. More specifically, research should focus on a comparative assessment of the burden versus the benefit of antibiotic treatment among palliative populations, as well as examine predictive variables with respect to which clients may benefit from antibiotic treatment and to what extent.

The interRAI PC assessments were only conducted once for each client, although proximity to death ranged greatly from a few days to one year. While some measurements will remain stable, reassessments are required in order to capture changes in clients' health conditions and preferences for end of life treatments. Future research should determine the intervals at which palliative home care clients should be reassessed (e.g., based on proximity to death).

7.10 Conclusions

More than half of the palliative home care clients had at least one or more ERVH, three quarters were admitted and more than half of those admitted died in hospital. Some variability was observed with respect to ERVH by the time of day and day of the week.

This study suggests that clients with increased use of end of life home care services use ED and hospital less often. Clients who did not have an ERVH had higher average cost of services, specifically increased hours of nursing and personal support services which perhaps allowed service providers to anticipate and address client needs in the home; thereby avoiding ERVH.

Contrary to most literature emphasizing that need, both perceived and evaluated, is the primary determinant of ERVH in older adults in the general population, this study indicates that among palliative home care clients predisposing characteristics (wish to die at home and advanced care directives) may be just as important as need variables (CHESS 3+, prior pneumonia, and prior urinary tract infections) in predicting ERVH.

Many of the assessed needs expected to drive ERVH were not predictors. Clients whose needs were assumed to be the greatest based on CHESS scores of 3+, indicating increased frailty and health instability, had reduced odds of ERVH. In general, clients with unstable health may be closer to death and may be more adjusted psychologically and emotionally to their illnesses. Therefore, clients' proximity to expected death may explain the negative association with ERVH use if death at home was the preferred outcome. For example, clients in close proximity to death might have preferred increased comfort care provided through formal services at home over

aggressive treatments provided in hospital settings. Other factors that contribute to ERVH among palliative home care clients require further consideration (e.g., injury, choking).

These findings point to the potential benefit of specifying the intervals at which palliative clients should be reassessed with the interRAI PC. Ongoing assessments may be essential in reducing ERVH as they will allow for care and service plans to be adjusted based on clients' changing health needs and end of life preferences.

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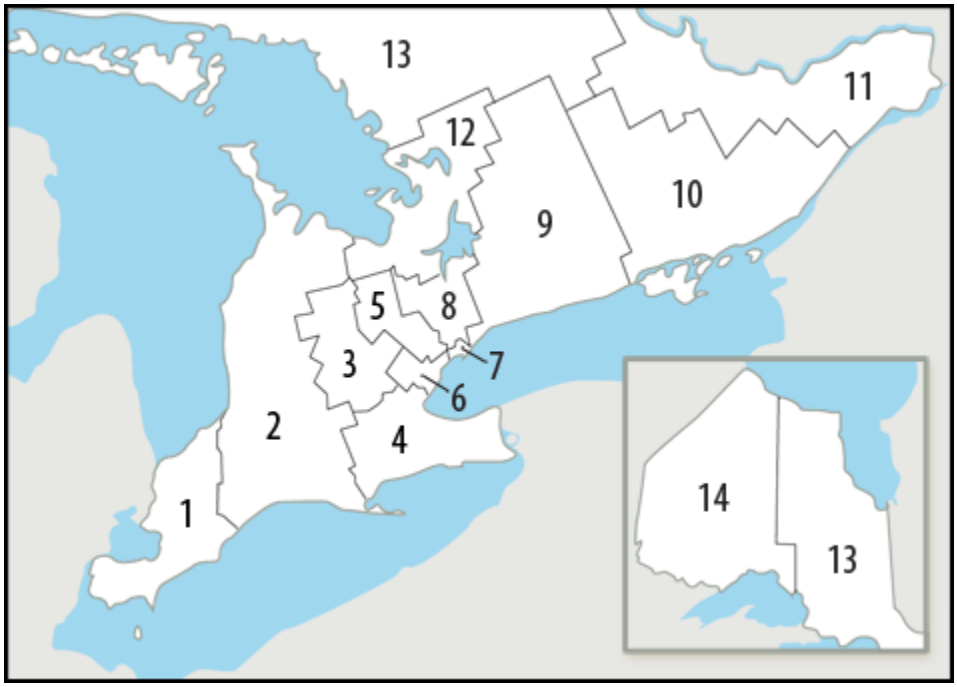
APPENDICES

APPENDIX A: LHIN/CCAC Map



(Source: Community Care Access Centres of Ontario)

1.Erie St. Clair
2.South West
3.Waterloo Wellington
4.Hamilton Niagara Haldimand Brant
5.Central West
6.Mississauga Halton
7.Toronto Central
8.Central West
9.Central East
10.South East
11.Champlain
12.North Simcoe Muskoka
13.North East
14.North West

APPENDIX B: Summary of 4 Studies Assessing the Impact of Hospice Palliative Care on Reducing Emergency Department Visits or Acute Hospital Admissions

Ref #, Author & Country	Type of study & Criteria	Sample	Type of Institution & Survival	Confounders Addressed	Statistical Significance	Key Findings
#17.Miccinesi et al. (2003) Tuscany, Italy	Retrospective cohort study Cancer patients died in 1997 Last year of life	Total N=3,423 N = 314 in palliative home care N=3,109 did not receive palliative care	Home care Median survival = 30.1 days	Age Sex Marital status Residency	53.2% of exposed had at least 1 hospitalization vs. 67.2% of unexposed ($p < 0.001$) Exposed had a 25% reduction in relative risk of hospitalization (CI: 14-34%) Exposed had 49% reduction in relative risk of spending days in hospital (CI: 47-52%)	Reductions were seen in last 6 months and 3 months Reasons: diagnostic procedures and chemotherapy Client characteristics associated with HPC: Female gender, younger than 75 years, married, cancer diagnosis
#45.Bergman et al. (2009) United States	Prospective cohort study All tumour grades, disease stages or history of	Total N=57 deceased N=16 in hospice 1 ERV = 13% 2 or more = 32%	Hospice program Median survival = 44 days	Marital status Race Residency Job status Income	Difference was not statistically significant	69% of patients enrolled in HPC did not visit hospital compared to 27% of those who were not enrolled Men who have never married were less likely to use hospice

	previous treatment	N=41 did not receive hospice care 1 ERV =41% 2 or more = 19%				programs
#46.Miller et al. (2001) United States	Retrospective cohort study Received services between 1992 and1996 Died before January 1998 Last 30 days of life	Total N=36,702 N=9,202 hospice patients N = 27, 500 non-hospice patients	Hospice care in nursing homes	Age Sex Marital status Race Cognitive performance scale Advanced directives	Hospice enrolment associated with reduced likelihood of hospitalization (odds ratio 0.43; 95% CI: 0.39-0.46)	24% of exposed were hospitalized vs. 44% of unexposed Those enrolled in HPC for entire 30 days: 1% of exposed were hospitalized vs. 42% of unexposed Client characteristics associated with HPC: female and advanced directives
#47.Costantini et al. (2003) Genoa, Northern Italy	*Retrospective cohort Study Advanced cancer deaths in 1991 Last 6 months of life	N=189 Exposed N=378 Unexposed receiving usual care from hospital, general practitioner or other health services	Home care Median survival = 49 days	Age Sex Marital status Education Primary tumour	Percentage of days spent in hospital was lower for the exposed (19.0%; 95% CI: 15-23) vs. the unexposed (30.3%; 95% CI: 26-34)	Percent of exposed and unexposed in hospital was- 60 days before death: 20% vs. 24% 30 days before :19% vs. 40% On day of death: 40% vs. 70%

Note: HPC= hospice palliative care; CI = confidence interval.

APPENDIX C: Summary of 4 Studies Assessing Factors that Contribute to Emergency Department Visits or Acute Hospital Admissions

Ref #, Author & Country	Type of Study	Sample Size	Type of Institution	Confounders Addressed	ERVH	Key Contributing Factors
#18.Cintron et al. (2003) United States	Retrospective cohort study Deaths between Jan1 1998 to Dec 31 1998 Last 6 months of life	N=14,056 Lung Cancer N=9543 Colorectal Cancer N= 22,185 died without being hospitalized	Hospice care Median survival = 25 days	Age Sex Marital status Race Residency Income	Only 6% were hospitalized 16% admitted more than once 36% died in hospital	Reasons: Lung cancer, metastic cancer, bone fracture, pneumonia and volume depletion, pleural effusion, delirium, psychiatric disorder, cardiac arrhythmia Client characteristics: African American, young age, male gender, those in denial of their diagnosis, and who withdrew from hospice to receive more aggressive therapy
#23.Schonwetter et al. (2008) United States	Retrospective cohort study Death in the year 2006 End stage cardiac disease	N = 145	Hospice care Median survival = 31 days	Age Sex Marital status Race Education DNR	N= 65 with at least one ERVH	Reasons: chest pains, diabetes, peripheral vascular disease, chronic pulmonary disease, asthma, hyper-lipidemia, palpitations Reduced risk: DNR, older age, increased nursing and chaplain visits, medications, caregivers at home, hospice emergency kit
#24.Olsen et al. (2011) United States	Retrospective cohort study Death in the year 2007	N = 46	Hospice care	Age Sex Residency	33 hospital visits 19 patients died in hospital	Reasons: delirium, pain, falls treatment of less common symptoms, COPD, congestive heart failure, dementia Client characteristics:

						younger age, Caucasian, cancer
#48.Lawson et al. (2008) Nova Scotia, Canada	Retrospective Cohort Study Deaths between January 1999 to December 2005	N=4,444	Home care Long-term care Inpatient palliative care unit Median survival = 68 days	Sex Age Residency Caregiver relationship	N=1182 of 4444 (26.6%) had 1 or more ED visits Reduced visits for those in long term care and home care	Pain, shortness of breath/dyspnea Weakness/malaise/fatigue Confusion/unconsciousness/dizzy Nausea/vomiting Bleeding, fever, falls/fractures/trauma/lacerations Client characteristics: younger age had increased use, age was a significant factor for women alone, rural residency was significant for women as well Clients cared for by parent more likely to make visits than if cared for by spouse
#49. Brink et al. (2011) Ontario, Canada	Retrospective cohort study Last 6 months of life	N=93	Home care	Age Sex Marital Status DNR	35% (n=33) used the ED Of the 33, 14 only used ED once, 11 used it two or more times	Predictors: weight loss, male gender, previous hospitalization Reduced risk: low cognitive function

Note: ED = emergency department; ERVH= emergency room visits and/or hospitalizations; DNR = Do-not-resuscitate-order.

APPENDIX D: Summary of Studies that Have Used the Andersen-Newman Framework to Predict Emergency Department Visits or Acute Hospital Admissions among Older Adults

Author & Country	Sample	Service	Most important predictors of service use
Wolinsky et al., 1984 United States	Non-institutionalized seniors	Physician visits Hospital admissions	*Need variables – limited activity, overall health
Evashwick et al., 1984 United States	Community dwelling seniors	Physician visits Hospital admissions	Predisposing characteristic – older age *Need variables – physical conditions, reduced ADL, perceived health status
Parboosing, J et al., 1987 Canada	Non-institutionalized seniors	Emergency department visits	Predisposing characteristics – attitude toward health care, prior experience with hospital systems Enabling factors – number of sources of health care
Chappell et al., 1987 Manitoba, Canada	Seniors 65 and older using Adult Day Care services or home care services	Physician visits Hospital admissions	<u>Physician visits:</u> Predisposing characteristics – widowhood, religion, occupation <u>Hospital admissions:</u> *Need variables reduced ADL, poorer perceived health
Penning, 1995 United States	Non-institutionalized seniors	Physician visits Hospital admissions	<u>Physician visits:</u> *Need variables – more chronic conditions, poorer levels of perceived health <u>Hospital admissions:</u> *Need variables – more chronic illnesses, reduced instrumental activities of daily living, increased social support
Stathers et al., 1996	Community dwelling seniors	Hospital admissions	*Need variables – medical need, reduced ADL function, acute illness, perceived health

Australia			
Weissert et al., 1997 United States	Home care clients	Hospital admissions	Predisposing characteristic – older age *Need variables – reduced ADL, Cancer
Bazargan et al., 1998 United States	Community dwelling senior African Americans	Physician visits Emergency department visits Hospital admissions	<u>Physician visits:</u> % accounted for variance -Predisposing: 12.8% -Predisposing+ enabling: 23% -Predisposing + enabling + need: 35.5% Predisposing characteristics and enabling factors accounted for most of the variance in physician visits <u>Emergency department visits:</u> -Predisposing: 16.5% of variance Predisposing + enabling: 20% -Predisposing + enabling + need: 33.6% <u>Hospital admissions:</u> -Predisposing: 10.7% -Predisposing +enabling: 12.1% -Predisposing + enabling + need: 26.3% Need variables accounted for most of the variance in hospital admissions
Culler et al., 1998 United States	Community dwelling seniors	Hospital admissions	Predisposing characteristics – older age, race Enabling factors – urban community *Need variables – perceived health status, coronary artery disease, diabetes, myocardial infarction, reduced ADL
Shash et al., 2001	Non-institutionalized	Emergency department visits	Predisposing characteristics – lower income

United States	seniors		*Enabling factors – older age, less education, living alone *Need variables – high co-morbidity scores, worse perceived health, reduced ADL
Shash et al., 2003 United States	Community dwelling seniors	Emergency department visits	*Need variables – immobility, acute illness symptoms, reduced ADL, reduced social functioning, perceived medical needs
Bowen et al., 2008 United States	Community dwelling seniors	Physician visits Hospital admissions	Among African Americans and Latinos *Need variables – reduced ADL, reduced mobility disability
Shibusawa et al., 2010 United States	Community dwelling Asian Indian seniors	Physician visits Emergency department visits Hospital admissions	<u>Physician visits:</u> Need variables – # of medical conditions <u>Emergency department visits & hospital admissions:</u> Enabling factors – age & medical insurance
Fan et al., 2011 United States	Community dwelling rural seniors	Emergency department visits	Predisposing characteristics – windowed, education Enabling factors – insurance *Need variables – poor perceived physical health, injury, respiratory disease and heart disease

Note: *explains most of the variance in service utilization

APPENDIX E: University of Waterloo, Office of Research Ethics Full Approval

UNIVERSITY OF WATERLOO
OFFICE OF RESEARCH ETHICS

Feedback on Ethics Review of Application to Conduct Research with Humans

All research involving human participants at the University of Waterloo must be carried out in compliance with the Office of Research Ethics Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

ORE File #: 17640

Project Title: Factors Influencing Emergency Room Visits and or Hospitalizations Prior to Death Among Hospice Palliative Care Clients from the Community

Faculty Supervisor: Dr. John Hirdes **Department/School:** Health Studies & Gerontology

Student Investigator: Lialoma Salam **Department/School:** Health Studies & Gerontology

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The above research application has undergone ethics review through the Office of Research Ethics and received the following ethics review category:

☐ **Ethics Clearance**. The application is considered acceptable on ethical grounds and complies with ORE Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. No revisions are required.

CONDITIONS ASSOCIATED WITH ETHICS CLEARANCE:
1. Ethics clearance is valid for five years from the date ethics clearance is granted.
2. Projects must be conducted in accordance with the description in the application for which full ethics clearance is granted. All subsequent modifications to the protocol must receive prior ethics clearance through the Office of Research Ethics.
3. An annual progress report (ORE Form 105) must be submitted for ethics review for each year of an ongoing project.
4. Any events, procedures, or unanticipated problems that adversely affect participants must be reported to the ORE using ORE Form 106.

☑ The application is considered acceptable on ethical grounds and complies with ORE Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. * **Minor/editorial revisions are required** as outlined in a transmitted email. Revised materials must be provided for the ORE file.

☐ Acceptance of the application on ethical grounds is **conditional on revisions and/or additional information**. The following revisions and/or additional information must be provided for ethics review and are requested within **10 days**. A study may not begin until it receives ethics clearance.

- ☐ Information Letter was not provided and is required for ethics review.
- ☐ Information Letter provided is incomplete and requires revisions outlined in the email message.
- ☐ Information Letter and Consent Form were not provided and are required for ethics review.
- ☐ Information Letter and Consent Form provided are incomplete and require revisions outlined in the email message.
- ☐ Copy of interview/survey questions was not provided and is required for ethics review.
- ☐ Other revisions/information are required as outlined in the email message.

☐ Due to the level and/or number of questions and concerns raised during the ethics review process the application is considered not acceptable on ethical grounds at this time . Comments are summarized in the attached ethics review feedback. A new application is required.

Susanne Santi 11/1/2011

Susan E. Sykes, Ph.D., C.Psych.
Director, Office of Research Ethics

Date

OR
Susanne Santi, M. Math
Senior Manager, Research Ethics

OR
Julie Joza, B.Sc.
Manager, Research Ethics

APPENDIX F: Hamilton Niagara Haldimand Brant CCAC Ethics Approval for Continuing Human Research Project

Dear Researcher:

Title: Hamilton Niagara Haldimand Brant (HNHB) CCAC Decision Support Contract
ORE #: 16597
Principal/Co-Investigator: John Hirdes (hirdes@uwaterloo.ca)
Principal/Co-Investigator: Jeff Poss (jwposs@uwaterloo.ca)
Student Investigator: Andrew Costa (acosta@uwaterloo.ca)
Student Investigator: Lia Salam (lsalam@uwaterloo.ca)

The annual progress report on Continuing Human Research for this project was received in the Office of Research Ethics in August 2011. Based on this, full ethics clearance of the corresponding continuing project is extended for another twelve-month period.

The information provided in the Progress Report has undergone ethics review through the Office of Research Ethics and is considered acceptable.

Note that submission of an annual progress report form is required for each year of the project.

Joanna Eidse, B.A,
Research Ethics Officer
Office of Research Ethics
NH 1024
519.888.4567 x 35217
jeidse@uwaterloo.ca

APPENDIX G: Hamilton Niagara Haldimand Brant CCAC Consent Form for Clients

Connecting you with care
Votre lien aux soins
CCAC CASC
Community Care Access Centre / Centre d'accès aux soins communautaires

Name	
Address	
Apt #	City
Postal Code	Client Reference#

AUTHORIZATION TO COLLECT, USE, & DISCLOSE PERSONAL HEALTH INFORMATION

I would like to review the CCAC's privacy practices with you. The CCAC needs your consent in order to collect, use, and share your personal health information with other health care organizations and our partners in your care. Your information is private. Unless sharing it is permitted by law, the CCAC will not give out any of your information without this consent.

I understand that the **HNHB** Community Care Access Centre and its contracted service providers collect your personal health information necessary for purposes related to the services they provide, including:

- determining your needs and coordinating the services that can be provided to you
- reviewing your needs and services on an ongoing basis
- directly or indirectly providing you with health and related social services
- monitoring the quality of services that you are receiving
- planning and evaluation of services
- prospective planning for your safety in disasters, emergencies, or evacuations, if required
- purposes permitted by law.

In order to provide you with these services, the CCAC and its service providers will share your personal health information with:

- authorized staff
- each other
- health care organizations, physicians and healthcare professionals involved in your care

And may share your information with:

- An authorized external agent for purposes of evaluation of CCAC services
- Municipal Office of Emergency Management, (Fire, Police, Ambulance), if required

As a CCAC client, you have the right to refuse to consent, restrict or to withdraw your consent at any time by contacting your Case Manager.

In addition, you also give the CCAC permission to collect and share your personal health information with the following person(s):

☐ **Personal Contacts:** _____
(name) (relationship) (phone #)

_____
(name) (relationship) (phone #)

☐ **Community Resources & Other:** _____
(name) (relationship) (phone #)

This consent is valid while you are receiving services. If at any time you want to make a change to this consent, please contact your Case Manager/Care Coordinator.

Do you understand and agree with all we have discussed? ☐ **Yes**

_____, **OR** _____,
Name of Client Substitute Decision-Maker

_____, _____,
Relationship (of SDM) Phone Number

☐ **Restriction(s) on consent**_____

*CM/CC Signature*_____ *Date:*_____
(obtaining verbal consent)

*Interpreter Name*_____ *Company/Individual*_____ *Language*_____

In case of an emergency and we cannot reach you, is there someone we can call to locate you? We will not be disclosing your personal health information to this person.

☐ superintendent ☐ neighbour
☐ friend ☐ personal contact as above
If yes, contact name:_____ Contact number:_____

CCAC March 2010

APPENDIX H: Resident Assessment Instrument- Palliative Care (interRAI PC)

Please visit http://catalog.interrai.org/catalog for information on how to obtain a copy of the interRAI PC.

APPENDIX I: Hamilton CCAC Agreement of Confidentiality

HAMILTON CCAC AGREEMENT OF CONFIDENTIALITY

I acknowledge that I have read, understood and received a copy of the CCAC Confidentiality Policy and agree to the following terms in this Agreement.

I acknowledge that during my employment/placement/volunteer/project work with the CCAC I may have access to confidential information.

I acknowledge that it is a term and condition of my work with the CCAC that I will at all times respect the privacy of clients and their families, CCAC students, volunteers and employees, and the confidential nature of the business of the CCAC.

I will closely protect confidential information to prevent it being inappropriately accessed, used or disclosed either directly by me, or by virtue of my password to systems, or by permitting breaches in physical security to occur.

I understand that violations to confidentiality may include, but are not limited to:

- Accessing personal or organizational information that I do not require in order to properly carry out my duties;
- Using or disclosing personal/organizational information (verbally, through the computer system, or in hard copy) without proper authorization;
- Inappropriately sharing passwords, keys, codes or other identification devices without proper authorization.

I will only access, use, transfer or disclose private and confidential information as required by the duties of my position.

I understand and agree to abide by the conditions outlined in this agreement both during and after my employment or association with the CCAC.

I understand that a violation of this agreement may result in disciplinary action that may include termination/dismissal from employment or association with the CCAC, or that I may be subject to civil or criminal liability.

Dated this _____day of _____, _____.

_____ _____

Name of Employee/Student/Volunteer Signature

_____ _____

Name of Witness Signature